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GESTÃO EM SAÚDE**

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**CONTRIBUIÇÃO DAS TICs PARA MELHORAR ASPECTOS DE  
ACESSIBILIDADE E AMPLIAR A INCLUSÃO EM UM SERVIÇO AMBULATORIAL  
DE ONCOLOGIA: UM ESTUDO À LUZ DO DESIGN INCLUSIVO**

**Porto Alegre**

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Dissertação de Mestrado apresentada ao Programa de Pós-Graduação em Tecnologias da Informação e Gestão em Saúde da Universidade Federal de Ciências da Saúde de Porto Alegre como requisito parcial para a obtenção do título de Mestre em Tecnologia da Informação e Gestão em Saúde

Orientador: Prof.<sup>a</sup> Dra. Cláudia de Souza Libânio

Co-Orientadores: Prof. Dr. Leandro Miletto  
Tonetto e Prof.<sup>a</sup> Dra. Emilene Zitkus de Andrade

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## RESUMO

O objetivo principal desta dissertação é propor soluções baseadas em TICs, à luz do design inclusivo, para contribuir com a melhoria de aspectos de acessibilidade e inclusão em um serviço ambulatorial de oncologia. Para alcançar esse objetivo, foram propostos objetivos específicos, que são respondidos por meio dos dois artigos. O primeiro artigo objetiva-se em compreender a estrutura das TICs em saúde para atender às necessidades de usuários com limitações. Através de uma revisão sistemática da literatura, estruturas para o design de TICs para usuários com limitações foram identificadas. O segundo artigo objetiva-se em: (i) identificar os pontos críticos da jornada do paciente quanto à acessibilidade e inclusão em um serviço ambulatorial de oncologia; (ii) compreender as necessidades de pessoas com deficiência e possíveis soluções para o serviço de saúde de acordo com suas necessidades; e (iii) discutir o potencial das TICs para melhorar aspectos de acessibilidade e ampliar a inclusão no serviço. Para isso, foi realizado um estudo de caso, com entrevistas com 13 pacientes, 5 acompanhantes e 4 profissionais de saúde, e observações não participantes em um serviço de oncologia. Além disso, um workshop com 10 pacientes, 2 acompanhantes, 5 profissionais da saúde, 7 pessoas com deficiência e 2 especialistas da área do design e das deficiências foi realizado. Os dados foram analisados por meio de análise temática. Foram observados pontos críticos relativos à acessibilidade e inclusão no serviço e foram identificadas oportunidades de implementação de TICs, destacando-se um aplicativo personalizado para o serviço. Essa solução resolveria muitas das barreiras identificadas, mas dependeria de uma estrutura voltada às necessidades dos usuários e de uma cultura inclusiva no serviço analisado. Como conclusão, identificamos que para que as TICs possam contribuir no contexto de análise, é necessário que sejam estruturadas de acordo com as necessidades dos usuários com deficiência, sejam implementadas de maneira a resolver pontos críticos de acessibilidade e inclusão do serviço, e façam parte de uma cultura inclusiva, que precisa começar muito antes de sua aplicação.

Palavras-chave: Design inclusivo. Acessibilidade. Inclusão. TICs. Oncologia. Serviços de saúde.

## **ABSTRACT**

*The main objective of this dissertation is to propose solutions based on ICTs, in the light of inclusive design, to contribute to the improvement of aspects of accessibility and inclusion in an outpatient oncology service. In order to achieve it, specific objectives were proposed, which are answered through two articles. The first article aims to understand the structure of health technologies to meet the needs of users with limitations. Through a systematic review of the literature, frameworks for designing ICTs for users with limitations were identified. The second article aims to: (i) identify the critical points of the patient's journey regarding accessibility and inclusion in a Brazilian outpatient oncology service; (ii) understand the needs of people with disabilities and possible solutions for the health service according to their needs; and (iii) discuss the potential of ICTs to improve aspects of accessibility and expand inclusion in the service. For this, a case study was carried out, with interviews with 13 patients, 5 companions and 4 health professionals, and non-participant observations in an oncology service. In addition, a workshop with 10 patients, 2 companions, 5 health professionals, 7 people with disabilities, and 2 specialists in the field of design and disabilities was held. Data were analyzed using thematic analysis. Critical points related to accessibility and inclusion in the service were observed and opportunities for implementing ICTs were identified, highlighting a customized mobile health application. This solution would solve many of the identified barriers, but would depend on a structure focused on user needs and an inclusive culture in the analyzed service. In conclusion, we identified that for ICTs to contribute in the context under analysis, it is necessary that they be structured according to the needs of users with disabilities, be implemented in order to solve critical points of accessibility and inclusion of the service, and be part of an inclusive culture, which needs to start long before its application.*

*Keywords: Inclusive design. Accessibility. Inclusion. ICTs. Oncology. Health services*

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## 1 INTRODUÇÃO

Os serviços de saúde têm se tornado cada vez mais complexos (BEGUN; THYGESON, 2015; BRAITHWAITE et al., 2017). O enfrentamento de desafios importantes, como incompatibilidade entre diretrizes e práticas, desintegração do cuidado e novas formas organizacionais e tecnológicas, têm aumentado significativamente a dificuldade de gerenciamento da área e experiências positivas dos usuários (GREENHALGH; PAPOUTSI, 2018). Ademais, a diversidade de partes interessadas, setores de atuação e tipos de instituições contribuem para o aumento do cenário de tamanha complexidade (BRAITHWAITE et al., 2017; KOOMANS; HILDERS, 2017).

O crescimento do envelhecimento populacional (DAMACENO; CHIRELLI, 2019; KAKEMAM et al., 2020) e o número de pessoas com deficiência ou mobilidade reduzida - que representa 15% da população global (WHO, 2020a) - são também fatores que contribuem para os desafios que se apresentam na área da saúde. Isso ocorre pelo surgimento de requisitos específicos, que precisam ser atendidos, de acordo com as peculiaridades e necessidades de respectivos grupos (GIRONDI; SANTOS, 2011).

O aumento da incidência de doenças crônicas não transmissíveis, como o câncer (MEETOO, 2008; CASADO; VIANNA; THULER, 2009; MALTA et al., 2017; SIMÕES et al., 2021), significa também o aumento na utilização dos diversos serviços de saúde (CASADO; VIANNA; THULER, 2009; MALTA et al., 2017). Ressalta-se o envolvimento de estratégias organizadas e proativas no manejo de doenças crônicas, que antecipem as necessidades dos pacientes, a fim de impedir complicações advindas da comorbidade (NORRIS et al., 2003). Evidencia-se, então, que gerenciar as especificidades complexas de pacientes com doenças crônicas torna-se mais um dos desafios aos serviços de saúde (WAGNER, 1998; HOLMAN, 2005), principalmente pelos sintomas físicos e mentais ocasionados pela doença e seus respectivos tratamentos (NAUGHTON; WEAVER, 2014).

Na perspectiva, gargalos relacionados à acessibilidade e à inclusão são também notórios nos serviços de saúde, tornando o acesso inadequado, além de

trazer prejuízos à experiência do usuário. Todas as pessoas podem enfrentar em algum momento da vida limitações, permanentes ou momentâneas (GOMES; QUARESMA, 2018), que influenciam nas perdas de capacidades, sejam elas relacionadas a visão, audição, pensamento, destreza e alcance, e mobilidade (CLARKSON et al., 2007). Salienta-se que, para essas pessoas - que podem enfrentar perdas de capacidades, sejam de berço ou ocasionadas pela idade, por acidentes, por doenças etc. - a falta de acesso físico, com adaptações e instalações acessíveis, a falta de materiais informativos, em Braille, com tamanho de letras adequados ou com a utilização de pictogramas, linguagem simples e presença de intérpretes, as atitudes negativas de preconceito por parte dos prestadores de saúde, a falta de treinamento dos profissionais, e a ausência de conhecimentos e habilidades necessárias/adequadas de provedores de saúde podem ser aspectos dificultadores de acesso aos serviços de saúde (UNDESA, 2016; WHO, 2020b).

Esses fatores têm impactado diretamente os usuários que estão em contato com os serviços de saúde, influenciando a jornada do paciente. Esta diz respeito às diversas interações entre os usuários do serviço com o sistema de saúde, provedores, familiares, acompanhantes e entre si, durante o processo do cuidado nas instituições (NASEM, 2018), com compartilhamento de ações e fluxos em inúmeros pontos de contato (GUALANDI et al., 2019). Durante a jornada do paciente, o usuário é exposto a diferentes interações pelos serviços de saúde, que, pelas contínuas mudanças do ambiente externo, novas leis e regulamentos, novas tecnologias, adaptação de decisões clínicas, novos direcionamentos na gestão e na organização do trabalho, entre muitos outros fatores que necessitam ser observados de maneira global, influenciam no decorrer do processo do seu cuidado (CARAYON et al., 2020).

Apesar da existência de estudos que explorem os processos de cuidado em saúde, com foco voltado ao profissional, suas atividades e atribuições na jornada do usuário, por vezes a perspectiva do paciente não é o foco principal (CARAYON; WOOLDRIDGE, 2020). Nesse sentido, a compreensão acerca da jornada do paciente precisa estar alicerçada com foco no usuário, suas expectativas, necessidades e

experiências na utilização do serviço (JAIN; AAGJA; BAGDARE, 2017; CARAYON; WOOLDRIDGE, 2020).

Tendo em vista os desafios enfrentados pela área da saúde e o impacto sobre a jornada do paciente, verifica-se que o design pode contribuir, no sentido de oferecer valor e benefícios para o campo de análise, compreendendo-o como uma maneira de entender múltiplas e complexas necessidades para projetar soluções e serviços que sejam capazes de supri-las (LIN et al., 2011). A complexidade existente nos serviços de saúde oportuniza ao design a contribuição para a localização e solução de problemas, bem como para o enfrentamento de barreiras e tendências emergentes em saúde (TSEKLEVES; COOPER, 2017). Ressalta-se, ainda, que na perspectiva de acessibilidade e inclusão em serviços de saúde, os conceitos do design inclusivo podem ser explorados, visto que buscam tornar produtos e serviços acessíveis para uma gama maior de indivíduos, incluindo pessoas com deficiência, mobilidade reduzida, e outras limitações físicas, cognitivas e/ou sensoriais (ZITKUS; LANGDON; CLARKSON, 2012).

Ainda neste contexto, observa-se que as tecnologias da informação e comunicação (TICs) possuem papel importante na definição de soluções em saúde, considerando seu potencial de gerar melhorias na qualidade dos serviços prestados. Podemos citar como exemplo o monitoramento remoto de sinais vitais (ANGERMANN et al., 2020), consultas médicas via telemedicina (ARIGHI et al., 2021), reabilitação por realidade virtual (KOHLLI et al., 2022), entre uma diversidade de inovações com base em tecnologias em saúde. As TICs no contexto da saúde trazem benefícios à experiência do paciente, aumentam a satisfação do provedor e do paciente, além de colaborarem positivamente com resultados institucionais, e com saúde da população como um todo (LI; CARAYON, 2021).

No entanto, não identificamos na literatura estudos que explorem em profundidade as oportunidades de implementação de TICs em serviços de saúde, com foco nos aspectos de acessibilidade e inclusão.<sup>1</sup> Alguns estudos exploram algumas tecnologias para auxiliar em aspectos de localização em instituições de saúde visando

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<sup>1</sup> A Revisão Sistemática da Literatura, apresentada no Artigo 1 desta dissertação, não identificou estudos com esse escopo.

públicos específicos com deficiência (LEE et al., 2020), outros propõem tecnologias assistivas em saúde também pensando em deficiências específicas (YANG et al., 2017), e outros, ainda, exploram soluções para problemáticas de acessibilidade e inclusão na saúde, sem a intersecção com TICs (LIU et al., 2018).

Diante do exposto, a lacuna que este estudo pretende investigar é a implementação de TICs no contexto de serviços de saúde, explorando oportunidades de contribuição com aspectos de acessibilidade e inclusão à luz do design inclusivo. Dessa forma, a pergunta que esta pesquisa busca responder é: como as TICs podem contribuir para melhorar aspectos de acessibilidade e ampliar a inclusão em um serviço ambulatorial de oncologia, à luz do design inclusivo? O foco do estudo são pacientes em tratamento oncológico que enfrentam alguma limitação prévia à doença, causada pela patologia e/ou pelo tratamento.

O subcapítulo seguinte trata do tema e objetivos do trabalho.

## 1.1 TEMA E OBJETIVOS

O tema desta dissertação de mestrado consiste na oportunidade de implementação de TICs para a melhoria de aspectos de acessibilidade e a ampliação da inclusão em um serviço de oncologia. A discussão acerca de soluções para a diminuição da exclusão de grupos minoritários em saúde está de acordo com os preceitos do design inclusivo (BURGSTAHLER, 2001; PATTISON; STEDMON, 2006; GOODMAN-DEANE et al., 2014; GOMES; QUARESMA, 2018). De acordo com Liu (2018), a abordagem do design inclusivo, quando aplicada à realidade dos serviços de saúde, traz inúmeras contribuições em relação a melhorias no acesso e na prestação dos serviços para todos os pacientes.

Para a busca de melhorias no escopo da acessibilidade e inclusão, este estudo abordará as TICs, explorando suas oportunidades de implementação no contexto, uma vez que elas têm sido apontadas como importantes aliadas do design na criação de inovações e avanços no que concerne à inclusão (AMPHILÓQUIO; SOBRAL, 2018).

Dessa forma, o objetivo geral desta dissertação consiste em propor soluções baseadas em TICs, à luz do design inclusivo, para contribuir com a melhoria de aspectos de acessibilidade e inclusão em um serviço ambulatorial de oncologia. A partir dessa análise, será possível entender as necessidades de acessibilidade do serviço, averiguar as oportunidades para soluções em TICs, e proporcionar melhorias para um serviço de saúde que lida com pessoas com diversas limitações físicas, cognitivas e sensoriais.

De modo a alcançar o objetivo geral, são elencados os objetivos específicos, que serão abordados nos artigos desta dissertação:

1. Compreender a estrutura das TICs em saúde para atender às necessidades de usuários com limitações, por meio de uma revisão sistemática de literatura;
2. Identificar os pontos críticos da jornada do paciente quanto a acessibilidade e inclusão em um serviço ambulatorial de oncologia;
3. Compreender as necessidades de pessoas com deficiência e possíveis soluções para o serviço de saúde de acordo com suas necessidades.
4. Discutir o potencial das TICs para melhorar aspectos de acessibilidade e ampliar a inclusão no serviço.

No subcapítulo seguinte apresenta a justificativa do trabalho.

## 1.2 JUSTIFICATIVA DO TRABALHO

O câncer gera uma série de mudanças e consequências no organismo, favorecendo o surgimento de barreiras. Os indivíduos diagnosticados com a patologia precisam, por vezes, passar por adaptações em seu estilo de vida devido aos efeitos causados pela doença e pelos respectivos tratamentos realizados (NAUGHTON; WEAVER, 2014). Se pensarmos na perspectiva da fragilidade e da limitação associada ao câncer, e no quanto seus diferentes tipos, diagnósticos e tratamentos afetam o paciente oncológico, podemos imaginar as diversas capacidades perdidas ao longo de todo o processo (HEWITT; ROWLAND; YANCIK, 2003; SWEENEY et al.,

2006; AZIZ, 2007; ROWLAND; BELLIZZI, 2008; NAUGHTON; WEAVER, 2014). Destacam-se visão, audição, pensamento, destreza, alcance, e mobilidade, que estão intimamente relacionadas com a percepção, pensamento e ação na interação com os serviços (CLARKSON et al., 2007).

É importante, nesse contexto, pensar nos diversificados perfis de pacientes oncológicos. Sabe-se que o câncer e o processo relacionado de tratamento, por si só, podem causar deficiências (HEWITT; ROWLAND; YANCIK, 2003). No entanto, o câncer pode acometer pessoas que já vivem em situação de perda de capacidades, com limitações momentâneas, temporárias ou permanentes, ou que fazem parte de grupos de maior vulnerabilidade. Por exemplo, idosos podem ser diagnosticados com câncer e, ao mesmo tempo, são mais propensos e experienciam outras comorbidades, doenças crônicas, delírio, demência, e mobilidade reduzida (CARRECA; BALDUCCI; EXTERMANN, 2005; ROH et al., 2014; ESTAPÉ, 2017). Outro exemplo são mulheres grávidas, que além das limitações temporárias que vivenciam em virtude da gestação, podem descobrir o câncer e experimentar as fragilidades causadas pelo tratamento (PAVLIDIS, 2011). Ademais, pessoas com deficiência, que já enfrentam limitações em suas vivências, podem ser diagnosticadas com câncer e passarem a enfrentar, além da sua perda de capacidades, novas barreiras concernentes à acessibilidade em seu dia-a-dia (SAKELLARIOU et al., 2019).

Dessa forma, é extremamente importante entender o quanto o câncer acomete na perda de capacidades, considerando a diversidade populacional existente, necessidades específicas, e a coexistência de vulnerabilidades. Além disso, é importante ressaltar que o acesso à saúde é um direito fundamental básico (RAMTIKTIN, 2011; SAKELLARIOU et al., 2019), que, dentre outros fatores, depende da acessibilidade aos serviços (LIU, 2018).

Estudos têm evidenciado que pessoas que enfrentam limitações, seja por deficiência ou mobilidade reduzida, encontram dificuldades relativas à acessibilidade no acesso a serviços de saúde, relacionadas a barreiras atitudinais e institucionais em relação ao preparo dos profissionais para lidar com os pacientes (SAKELLARIOU et al., 2019), falta de ambientes físicos preparados para lidar com as deficiências

(EDWARDS; SAKELLARIOU; ANSTEY, 2019), barreiras relacionadas a custo, transporte, insuficiência de recursos e dependência de outras pessoas para o acesso (HARRISON et al., 2020) etc. Considerando essa problemática, é importante que haja um questionamento em relação ao preparo dos serviços, em especial os de oncologia, para receber, acolher, lidar, e permitir o acesso sem barreiras a pessoas com perdas de capacidade, principalmente em decorrência da patologia. É necessário que serviços de oncologia sejam acessíveis e inclusivos para todas as pessoas, considerando todas as necessidades e especificidades (EDWARDS; SAKELLARIOU; ANSTEY, 2019).

É válido ressaltar, ainda, a realidade brasileira, que apesar de ter o direito à saúde assegurado pelo artigo 196 da Constituição Federal aos seus mais de 212 milhões de habitantes (BRASIL, 1988), enfrenta uma série de desafios na entrega dos serviços de maneira equitativa e universal (FERRAZ; VIEIRA, 2009). Por mais que existam políticas que assegurem o direito à saúde para todas as pessoas, e que voltem seu olhar àqueles que enfrentam limitações, nem sempre a prática se traduz em bons resultados, por vezes pela falta de recursos (CUNHA et al., 2022).

Frente a este conjunto de aspectos, surge a oportunidade de entender os gargalos concernentes à acessibilidade e à inclusão em um serviço de oncologia, considerando as perdas de capacidades e limitações vivenciadas por pacientes em tratamento para câncer. Salienta-se a oportunidade de o design inclusivo colaborar com os aspectos de inclusão e acessibilidade em saúde - considerando seu escopo de projeção para todas as pessoas (BURGSTAHLER, 2001; PATTISON; STEDMON, 2006; GOODMAN-DEANE et al., 2014; GOMES; QUARESMA, 2018) - bem como, das TICs nesse contexto, para auxiliarem na proposta de soluções no serviço, levando em conta as capacidades perdidas (ITU, 2013). Considerar-se-á, dessa forma, o apoio do design inclusivo para a proposição de soluções em TICs.

Visto isso, o presente trabalho justifica-se pela relevância do entendimento das perspectivas de acessibilidade e inclusão em um serviço de saúde de tamanha complexidade. O entendimento de quanto cada indivíduo em tratamento oncológico consegue perceber, pensar e agir no serviço ao longo de sua jornada, e a proposição de soluções nesse sentido, pode melhorar sua experiência, além de tornar o serviço

e o atendimento prestado acessíveis para todos os pacientes. Além disso, esta dissertação trata de uma temática que faz parte de uma preocupação global, estando contemplada pela Agenda 2030 da Organização das Nações Unidas. A temática da promoção de saúde e bem-estar faz parte do Objetivo de Desenvolvimento Sustentável (ODS) 3, e a inclusão está contemplada no ODS 10, que busca redução das inequidades e da discriminação (UN, 2023). Entende-se que esse trabalho perpassa esses dois objetivos, relacionando-os de maneira a incluir pacientes com limitações em serviços de saúde, para que tenham seu atendimento prestado com qualidade e suas demandas de saúde resolvidas.

À vista disso, o trabalho contribui com a área acadêmica, por suscitar a pesquisa e a discussão acerca de aspectos relativos à acessibilidade e à inclusão nos serviços de saúde, particularmente com olhar para a realidade brasileira. Ademais, a pesquisa traz contribuições em termos profissionais para a gestão dos serviços de saúde, na medida que tangencia tópicos que influenciam diretamente no acesso dos usuários aos serviços. O gestor em saúde necessita de uma visão holística do funcionamento dos serviços os quais lidera, sendo assim importante a busca pelo entendimento da qualidade da assistência prestada, do acesso sem barreiras e exclusões, da experiência do paciente em cada etapa do atendimento, e da jornada do usuário e possíveis pontos críticos existentes ao longo desse processo. Por último, esta dissertação traz contribuições além do escopo acadêmico e profissional, pela proximidade à realidade dos usuários do serviço de saúde, que poderão ser beneficiados pelos resultados da pesquisa e das soluções propostas.

O subcapítulo seguinte trata das delimitações do trabalho.

### 1.3 DELIMITAÇÕES DO TRABALHO

Por ter um caráter multidisciplinar, esta dissertação abrange conceitos de diferentes áreas do conhecimento, como Design, Gestão em Saúde e Tecnologias da Informação e Comunicação. Pela abrangência do escopo, torna-se inviável o esgotamento de todos os conteúdos propostos. Dessa forma, o trabalho é pautado, principalmente, pela teoria do Design Inclusivo, e traz aplicações em TICs de maneira

a contribuir com uma melhor prestação de serviços da área da saúde, o que traz importantes contribuições para a área da gestão.

De maneira mais específica, a área proposta para o estudo é um serviço de oncologia, pelo entendimento das fragilidades vivenciadas por esses pacientes e pelo interesse nas múltiplas vulnerabilidades que podem acometê-lo. No entanto, as deficiências podem ser fruto de outras comorbidades além do câncer, bem como pessoas com deficiências prévias podem desenvolver outras doenças e utilizar qualquer outro tipo de serviço de saúde. Dessa forma, os resultados encontrados na pesquisa podem ser aplicados para outros contextos, além dos serviços oncológicos, considerando que a acessibilidade precisa estar presente em todos os serviços, para que qualquer paciente, independente da condição, possa acessá-los sem barreiras.

O capítulo a seguir apresenta o delineamento do estudo.

## **2 DELINEAMENTO DO ESTUDO**

Neste capítulo consta o delineamento do estudo, com os métodos abordados e a estrutura da dissertação.

### **2.1 METODOLOGIA**

A metodologia está detalhada considerando os seguintes tópicos: delineamento; o caso em análise; procedimento de coleta dos dados; análise dos dados; questões éticas; e estrutura do trabalho.

#### **2.1.1 Delineamento**

Em relação à sua natureza, esta pesquisa é classificada como aplicada, visto que teve como finalidade gerar soluções a problemas existentes, buscando entender como lidar com estes problemas (ZANELLA, 2013). Quanto aos seus objetivos, a pesquisa é de caráter exploratório, visto que proporcionou maior familiaridade com o problema, por meio da aproximação do pesquisador com a temática de análise (MARCONI; LAKATOS, 2010). A abordagem do estudo é qualitativa, que permite uma melhor compreensão de fenômenos através da obtenção de dados descritivos sobre pessoas, lugares e processos interativos por meio do contato direto entre o pesquisador e as situações estudadas (GODOY, 1995). A exploração de detalhes, atitudes e percepções acerca de determinada temática é parte dessa abordagem (HUTTON, 1990). Por fim, no que concerne aos procedimentos técnicos adotados na coleta de dados, realizou-se pesquisa bibliográfica e um estudo de caso, considerando um primeiro momento com base em estudos já publicados, e um segundo momento com coleta de dados primários em unidade específica de estudo, a fim de trazer aprofundamento na temática estudada (ZANELLA, 2013). Nas subseções seguintes será apresentado o caso em análise, bem como o detalhamento dos procedimentos metodológicos deste trabalho.

## 2.1.2 O caso em análise

Nesta subseção será realizada a caracterização do cenário da pesquisa, com a descrição do contexto brasileiro e do caso a ser analisado.

### 2.1.2.1 O contexto brasileiro e o câncer

De acordo com o Instituto Nacional de Câncer brasileiro (INCA), devido ao crescimento exponencial do envelhecimento populacional no Brasil, houve também aumento na prevalência de câncer, demandando dos gestores em saúde empenho na oferta de acesso aos serviços, de maneira adequada e equitativa. Ademais, evidenciou-se a necessidade de investimentos em promoção de saúde, como forma de prevenção de doenças crônicas como o câncer (INCA, 2006).

De acordo com dados atuais do INCA, a estimativa para cada ano do triênio 2020-2022 no Brasil é de que a ocorrência de novos casos de câncer seja de aproximadamente 625 mil. Desses, destaca-se o câncer de pele não melanoma com maior incidência (177 mil), seguido pelos cânceres de mama e próstata (66 mil cada), cólon e reto (41 mil), pulmão (30 mil) e estômago (21 mil) (INCA, 2019).

No que concerne à mortalidade, no ano de 2019, o câncer de traqueia, brônquios e pulmões foi o que mais causou óbitos entre homens no Brasil, com 16.733 mortes, representando 13,8% da mortalidade por câncer entre o sexo masculino. O câncer de próstata foi o segundo com maior incidência de óbitos, representando 13,1% das mortes por câncer entre os homens. Entre as mulheres, a causa de mortes por câncer no mesmo ano esteve mais concentrada no câncer de mama, com 18.068 mortes, constituindo um percentual de 16,4%. O câncer de traqueia, brônquios e pulmões assumiu a segunda posição, com 11,4% das mortes por câncer entre o sexo feminino (INCA, 2021). Nota-se, então, os cânceres de traqueia, brônquios e pulmão, mama e próstata como os que mais causam mortes pela doença no país.

Em relação aos serviços oncológicos no cenário brasileiro, percebe-se disparidade na sua disponibilidade - fato que pode afetar a sobrevivência dos pacientes, a qualidade do atendimento, a qualidade de vida, além de influenciar em taxas de

mortalidade por câncer (SILVA; O'DWYER; OSORIO-DE-CASTRO, 2019). O estudo de Silva et al. (2020), realizado em um serviço de oncologia brasileiro, revela, ainda, que condições de vulnerabilidade social da população tornam o acesso aos serviços e aos tratamentos dificultoso, ainda que exista a Política Nacional de Atenção Oncológica, que assegura promoção, prevenção, diagnóstico, tratamento, reabilitação e cuidados paliativos em saúde. Muitos pacientes encontram dificuldades de deslocamento, vivem em cidades afastadas do serviço de referência, precisam aguardar o retorno às suas casas por longos períodos após a realização das sessões de quimioterapia e radioterapia etc., demonstrando que ficam, por vezes, desassistidos em muitos aspectos (SILVA et al., 2020). Esses fatores ressaltam algumas problemáticas vivenciadas pelo sistema de saúde brasileiro, que refletem no serviço de oncologia e na assistência prestada aos pacientes oncológicos.

#### 2.1.2.2 Unidade de análise do estudo

A unidade de análise deste trabalho foi a um Serviço de Oncologia em nível ambulatorial da cidade de Novo Hamburgo/ Rio Grande do Sul (RS), que possui aproximadamente 86 pacientes em atendimento. O serviço atende somente pacientes adultos, de maneira particular ou por convênios médicos, ofertando tratamento quimioterápico, tratamento imunoterápico, prevenção do câncer, quimioterapia via oral e assistência farmacêutica, infusão de terapias de suporte para pacientes oncológicos e apoio multidisciplinar. O estudo teve enfoque nos pacientes em tratamento quimioterápico.

O serviço está localizado em um centro clínico que conta com inúmeros serviços de saúde, desde exames, até atendimentos médicos e laboratoriais. No primeiro andar, a instituição oferece acesso a farmácias, ótica, bancos, operadoras de planos de saúde, café, clínica de vacinas e aparelhos auditivos. Nos oito andares restantes, encontram-se serviços de diagnósticos e consultórios médicos. O serviço encontra-se no primeiro subsolo do centro clínico, e os acessos à instituição podem ser realizados por um dos dois estacionamentos privativos disponíveis ou pela porta de entrada que dá acesso a uma calçada na avenida.

Fazem parte da equipe cinco oncologistas, quatro enfermeiras oncológicas, uma recepcionista e duas auxiliares administrativas. Os farmacêuticos, apesar de levarem os medicamentos solicitados ao serviço, trabalham em uma farmácia oncológica localizada em outro prédio próximo ao serviço. O serviço é composto por recepção, sala administrativa, copa, sala de arquivos, dois consultórios médicos e a área de quimioterapia, composta por cinco salas de quimioterapia, enfermaria e dois banheiros.

### **2.1.3 Procedimento de coleta dos dados**

O presente estudo foi dividido em duas etapas, sendo a primeira com a coleta de dados secundários, por meio de uma Revisão Sistemática da Literatura, e a segunda por meio da coleta de dados primários, configurando um estudo de caso único em campo específico. Nas subseções seguintes, ambas etapas serão explicadas e detalhadas.

#### **2.1.3.1 Revisão Sistemática da Literatura**

A primeira etapa desta pesquisa foi realizada por meio de uma Revisão Sistemática da Literatura (RSL), que consiste em um tipo de investigação focada em questão bem definida, de modo a identificar, selecionar, avaliar e sintetizar as evidências (GALVÃO; PEREIRA, 2014). Para a realização da RSL, foram utilizadas como base as etapas propostas por Arksey e O'Malley (2005): (I) identificar as questões de pesquisa; (II) identificar estudos relevantes; (III) selecionar estudos; (IV) mapear os dados; e (V) reunir, resumir e relatar os resultados. Especificamente para a etapa de seleção dos estudos, foi utilizado como base o fluxograma de quatro etapas recomendado pelo método PRISMA: (I) identificação; (II) triagem; (III) elegibilidade; e (IV) inclusão (MOHER et al., 2015). O protocolo da RSL encontra-se no APÊNDICE A.

### 2.1.3.2 Estudo de Caso

De acordo com Zanella (2013), o estudo de caso permite aprofundamento no conhecimento sobre determinada temática, uma vez que busca entender uma realidade em profundidade. Esta etapa da pesquisa foi dividida em dois momentos: 1) mapeamento da jornada do usuário; e 2) workshop. O mapeamento da jornada do usuário contou com três técnicas de coleta de dados: observação não participante; entrevistas em profundidade com profissionais envolvidos no serviço; e entrevistas em profundidade com usuários e familiares/acompanhantes. O segundo momento consistiu em um workshop com usuários (pacientes com e após o câncer), familiares/acompanhantes, profissionais de saúde, pessoas com deficiência e especialistas/pesquisadores da área do design e deficiências. A combinação das técnicas indicadas nos dois momentos teve como propósito a compreensão da jornada do paciente e os pontos críticos do serviço concernentes à acessibilidade e à inclusão, as necessidades de pessoas com deficiência e a identificação de oportunidades de melhoria no serviço analisado.

#### 2.1.3.2.1 Primeiro momento: Mapeamento da jornada do usuário

Para o primeiro momento da etapa exploratória foram utilizadas três técnicas de coleta de dados: (a) observação não participante; (b) entrevistas em profundidade com profissionais envolvidos no serviço; e (c) entrevistas em profundidade com usuários e familiares/acompanhantes. Em seguida serão detalhadas todas as técnicas utilizadas.

##### (a) Observação não participante

A observação não participante é uma técnica de coleta de dados em que o pesquisador utiliza a observação para buscar entender o mundo, as interações e as relações. Nesta técnica o observador não tem qualquer envolvimento ou interação humana no campo de pesquisa (CIESIELSKA; BOSTRÖM; ÖHLANDER, 2018),

atuando como “espectador temporário que, com base nos objetivos da pesquisa, elabora um roteiro de observação e registra os fatos que interessam ao seu trabalho” (ZANELLA, 2013).

Nesta pesquisa, a observação não participante foi realizada de maneira presencial no serviço, durante 15 dias nos turnos e dias combinados previamente com o serviço, de acordo com a disponibilidade e preferência. Foram totalizadas em torno de 24 horas de observações. Tudo o que foi observado teve relação direta com a jornada do usuário no serviço, buscando-se observar os pontos críticos relacionados à inclusão e à acessibilidade do paciente ao longo de sua jornada (desde o momento que chega no serviço até o momento de sua saída), como forma de identificação de oportunidades de melhoria. Algumas observações ocorreram também nos momentos durante/pós-entrevista, em que a entrevista era interrompida pelo fluxo do serviço, como, por exemplo, entrada da equipe de enfermagem para administração de quimioterapia. Além disso, essa técnica de coleta de dados serviu para que os pesquisadores conhecessem toda a instituição, suas portas de entrada, presença ou ausência de recursos de acessibilidade de acordo com as normas regulatórias, placas e sinalizações etc.

As informações coletadas nas observações foram registradas em um diário de campo (APÊNDICE B), incluindo as anotações, observações e registros fotográficos que foram realizados (com o consentimento dos participantes e sem identificação de quaisquer envolvidos). Os pesquisadores se posicionaram em pontos estratégicos da instituição e do serviço, de forma a facilitar o mapeamento do dia-a-dia de atendimento, e as questões pontuais da assistência, considerando as particularidades e vivências de cada paciente, familiar/acompanhante e profissional. É importante ressaltar que a coleta de dados pela observação não participante não provocou nenhuma interferência na rotina do serviço de oncologia, bem como não prejudicou seu fluxo diário. Como forma de garantir que os pesquisadores não fizessem interferências, foi combinado com a equipe os melhores locais para se posicionar, de modo a operacionalizar a observação, sem atrapalhar os fluxos ou constranger os participantes da pesquisa e trazer descontentamento com o atendimento.

### (b) Entrevistas em profundidade com profissionais envolvidos no serviço

A entrevista em profundidade consiste no envolvimento verbal entre o pesquisador e o participante, considerando a relação do entrevistado com o processo que está sendo analisado. Este tipo de entrevista é marcado por flexibilidade na estrutura das questões, permitindo que os tópicos sejam explorados de maneira aprofundada, além de possibilitar a reflexão sobre sentimentos, emoções, crenças e experiências na perspectiva do entrevistado (COOMBES et al., 2009).

As entrevistas em profundidade foram realizadas de junho a setembro de 2022 com 4 profissionais do serviço de oncologia, sendo 3 enfermeiras oncológicas e 1 médica, também proprietária e responsável técnica da clínica. Os profissionais foram selecionados de acordo com o interesse e disponibilidade de participação, uma vez que todos tinham envolvimento com os pacientes oncológicos. A entrevista com as enfermeiras ocorreu ao mesmo tempo, reunindo o ponto de vista das três profissionais, de maneira presencial no serviço, em um turno previamente combinado sem pacientes em atendimento. A entrevista com a médica também aconteceu no serviço em um horário sem atendimento de pacientes. As entrevistas foram gravadas e, posteriormente, transcritas.

A entrevista com as enfermeiras teve duração de 2 horas, e a entrevista com a médica durou 1 hora. Ambas foram guiadas por um roteiro de questões norteadoras, definidas no roteiro de entrevista semiestruturada (APÊNDICE C). O intuito principal da etapa foi averiguar a percepção dos profissionais sobre o serviço no qual atuam, evidenciar sua compreensão e opinião sobre aspectos de acessibilidade e inclusão dos pacientes oncológicos no serviço, e entender de maneira mais aprofundada sobre todas as etapas e pontos de contato da jornada dos usuários pelo serviço.

### (c) Entrevistas em profundidade com usuários e familiares/acompanhantes

Foram entrevistados 13 pacientes, 5 familiares/acompanhantes no período de junho a setembro de 2022 de maneira presencial no serviço de oncologia. Os pacientes foram selecionados por conveniência, conforme disponibilidade e interesse

em participar da entrevista. Para isso, as enfermeiras perguntaram aos pacientes em tratamento quimioterápico, nos dias em que os pesquisadores estavam no serviço, quem gostaria de ser entrevistado. Aqueles que aceitaram foram selecionados. Em relação aos acompanhantes, também foram selecionados aqueles que manifestaram interesse em participar. Os pacientes foram entrevistados durante a sessão de quimioterapia e os acompanhantes foram entrevistados durante a sessão de quimioterapia do paciente na mesma sala ou em uma sala separada. Isso deu-se porque alguns acompanhantes participaram da entrevista com os pacientes e outros optaram por dar a entrevista de maneira separada.

As entrevistas ocorreram por meio de um roteiro de questões norteadoras, conforme roteiro de entrevista semiestruturada (APÊNDICE D), que buscou verificar a percepção dos usuários, seus familiares e acompanhantes sobre o serviço de oncologia, como forma de entender sua experiência no serviço, dificuldades enfrentadas, e barreiras encontradas no que concerne à acessibilidade e à inclusão. Além disso, esse roteiro buscou coletar informações sobre a condição do usuário, suas capacidades perdidas ao longo do tratamento, se já possuía condição prévia de limitação, entre outras informações alinhadas nesse sentido. A duração das entrevistas teve uma média aproximada de 1 hora, tendo sido gravadas e transcritas posteriormente.

#### *2.1.3.2.2 Segundo momento: Workshop*

Depois de coletar e analisar os dados das entrevistas e observações, foi realizado um workshop, que consiste em uma ferramenta de design que gera ideias, conceitos e soluções para problemas identificados e apresentados (LIMA et al., 2016). O workshop ocorreu no mês de março de 2023, em um único encontro de 3 horas em uma universidade, foi conduzido por dois pesquisadores, e reuniu 10 pacientes oncológicos (em tratamento e após o câncer), 2 familiares/acompanhantes, 5 profissionais de serviços de oncologia, 7 pessoas com deficiência (duas pessoas com deficiência visual, três pessoas com deficiência auditiva e uma pessoa com deficiência física) e dois especialistas/pesquisadores da área do design e deficiências (um deles

também era intérprete de língua de sinais). Os convites para participar da oficina foram enviados aos funcionários do serviço de oncologia e divulgados por eles nas redes sociais, reforçando a presença de pacientes, acompanhantes e profissionais do serviço analisado ou de outros serviços. As pessoas com deficiência e os especialistas foram contatados por meio das redes profissionais dos pesquisadores.

O intuito dessa etapa foi apresentar a jornada dos pacientes aos participantes do workshop, destacando as barreiras relativas à acessibilidade e inclusão evidenciadas, a fim de que fossem discutidas soluções. Algumas soluções prévias em TICs foram apresentadas e os participantes foram instigados a discutir sobre tecnologias como soluções ao contexto. O envolvimento de pessoas com deficiência externas ao serviço deu-se pelo fato de que não foram evidenciados no serviço analisado (nas entrevistas e observações) pessoas cegas, surdas e cadeirantes que já tivessem chegado com essa condição para o tratamento oncológico. Os pacientes entrevistados apresentaram limitações prévias e decorrentes da doença, mas não trouxeram o escopo específico de algumas deficiências. O entendimento dessas pessoas sobre a jornada dos usuários e tecnologias para o contexto foi considerado importante, e por isso elas foram convidadas a cocriar no workshop. Isso está de acordo com a literatura de design inclusivo, que coloca a importância de envolver uma diversidade de usuários no desenvolvimento de soluções (FUGLERUD; HALBACH; SNAPRUD, 2021).

O workshop seguiu o método de design *thinking* baseado nas quatro etapas sugeridas por Kelley e Kelley (2013): 1. Inspiração; 2. Síntese; 3. Ideação e experimentação; e 4. Implementação. O roteiro e o cronograma do workshop, bem como as etapas e dinâmicas realizadas encontram-se no APÊNDICE E.

#### **2.1.4 Análise dos dados**

A análise, tanto dos dados bibliográficos da RSL, quanto dos dados qualitativos gerados pelo estudo de caso, deu-se por meio da análise temática, que consiste em uma técnica de pesquisa que apresenta como característica a flexibilidade, sendo utilizada para identificar, analisar e relatar padrões (temas) dentro dos dados. De

maneira geral, ela organiza e descreve o conjunto de dados em detalhamento (BRAUN; CLARKE, 2006). Essa análise foi escolhida, uma vez que tem sido amplamente utilizada na pesquisa em design (LIN, 2018; TONETTO et al., 2021) e por possibilitar um modo flexível de análise dos dados qualitativos.

#### 2.1.4.1 Dados bibliográficos

Os dados bibliográficos coletados dos artigos utilizados na RSL foram organizados em uma tabela, com as seguintes categorias de análise: título do artigo; ano de publicação; nomes dos autores; local de publicação; periódico publicado; objetivo; procedimento de pesquisa utilizado; tema principal; público-alvo de análise; limitações identificadas; tecnologias aplicadas/trabalhadas no artigo; estruturas para atender usuários com limitação; contribuições da aplicação para a acessibilidade e a inclusão; desafios de implementação; resultados da pesquisa; e relações com o design inclusivo. Para a resposta da principal pergunta do artigo (sobre as estruturas das tecnologias), os temas surgiram de maneira indutiva (orientada pelos dados, definição *a posteriori*) e dedutiva (orientada por teoria, definição *a priori*). Para as perguntas sobre barreiras e contribuições os temas surgiram a partir dos dados (BRAUN; CLARKE, 2006).

#### 2.1.4.2 Dados das entrevistas e observações

Em relação às entrevistas e observações, a análise temática teve início pela leitura das falas das entrevistas realizadas por meio das transcrições das gravações das coletas, bem como por meio das notas de observações realizadas pelos pesquisadores. Os dados transcritos foram lidos e relidos. Temas foram definidos *a priori* com base nas barreiras de acessibilidade propostas por Sassaki (2009). Códigos iniciais foram gerados no conjunto de dados e, posteriormente, distribuídos nos temas. Essa análise ocorreu em uma tabela, com os conjuntos de dados respectivos a cada tema diferenciados por cor. Por último, foram realizadas as conferências finais, com a identificação e seleção de extratos que pudessem exemplificar os temas em questão,

e a relação com a literatura, conforme recomendado por Braun e Clarke (2006). O intuito do agrupamento por categorias temáticas nesta etapa da pesquisa foi buscar entender a jornada do usuário, as diferentes barreiras que se fazem presentes, bem como visualizar as dificuldades enfrentadas em cada uma das etapas.

Depois disso, foi utilizada como ferramenta de auxílio um mapa da jornada do usuário, que permitiu a visualização da jornada dos usuários pelo serviço analisado, com a identificação das principais interações (LIU, 2018). O mapa ilustrou as etapas percorridas, identificou todas as capacidades necessárias dos usuários para as demandas do serviço, bem como sinalizou os pontos críticos de acessibilidade e inclusão e as oportunidades para a implementação de soluções em TICs.

#### 2.1.4.3 Dados do workshop

Em relação ao workshop, a análise temática teve início pela leitura da transcrição realizada. Os dados transcritos foram lidos e relidos e temas foram definidos a partir dos dados, tendo sido denominados como: (i) soluções para os serviços de saúde; e (ii) soluções para além dos serviços. A análise foi feita da mesma forma que com as entrevistas e observações, conforme as orientações de Braun e Clarke (2006).

Os resultados obtidos no workshop foram utilizados para sustentar as soluções propostas e como forma de entender algumas necessidades mais específicas de pessoas com deficiência, relativas às suas dificuldades diárias pela falta de acessibilidade nos mais diversos espaços, aos cuidados em saúde e aos seus pontos de vista sobre melhorias que façam sentido para suas limitações. Essas necessidades específicas não foram identificadas no serviço analisado de maneira aprofundada, pela ausência de pacientes com perda total de visão, audição, e pacientes com alguma condição mais grave de perda cognitiva, por exemplo.

### **2.1.5 Questões éticas**

A pesquisa faz parte de um projeto mais amplo sobre as potencialidades do design na experiência do usuário em serviços de saúde. Este projeto segue as diretrizes da Resolução nº 466/2012 do Conselho Nacional de Saúde sobre pesquisas com seres humanos, foi aprovado pelo Comitê de Ética em Pesquisa da Universidade Federal de Ciências da Saúde de Porto Alegre (UFCSPA), sob o número CAAE 55467222.5.0000.5345, conforme ANEXO A, e possui termo de anuência assinado pela diretora médica do serviço analisado.

Todas as etapas da pesquisa que envolveram seres humanos contaram com a assinatura de um Termo de Consentimento Livre e Esclarecido (TCLE) por parte dos participantes. Além disso, os pesquisadores disponibilizaram para leitura dos participantes um Termo de Compromisso de Utilização de Dados (TCUD), assinado por todos os membros da equipe de pesquisa.

### **2.1.6 Estrutura do trabalho**

Esta dissertação de mestrado está organizada em formato de artigos científicos, conforme orientações do Programa de Pós-Graduação em Tecnologias da Informação e Gestão em Saúde da Universidade Federal de Ciências da Saúde de Porto Alegre (PPGTIGSaúde/UFCSPA). O trabalho está dividido em dois artigos científicos, escritos em inglês. O primeiro já foi submetido e está formatado de acordo com as diretrizes do periódico. O segundo será submetido após a defesa da dissertação e, por isso, ainda não está formatado para um periódico em específico. O referencial teórico da dissertação está dividido entre eles. A seguir, será apresentada uma breve contextualização dos dois artigos, para melhor compreensão da estrutura do trabalho.

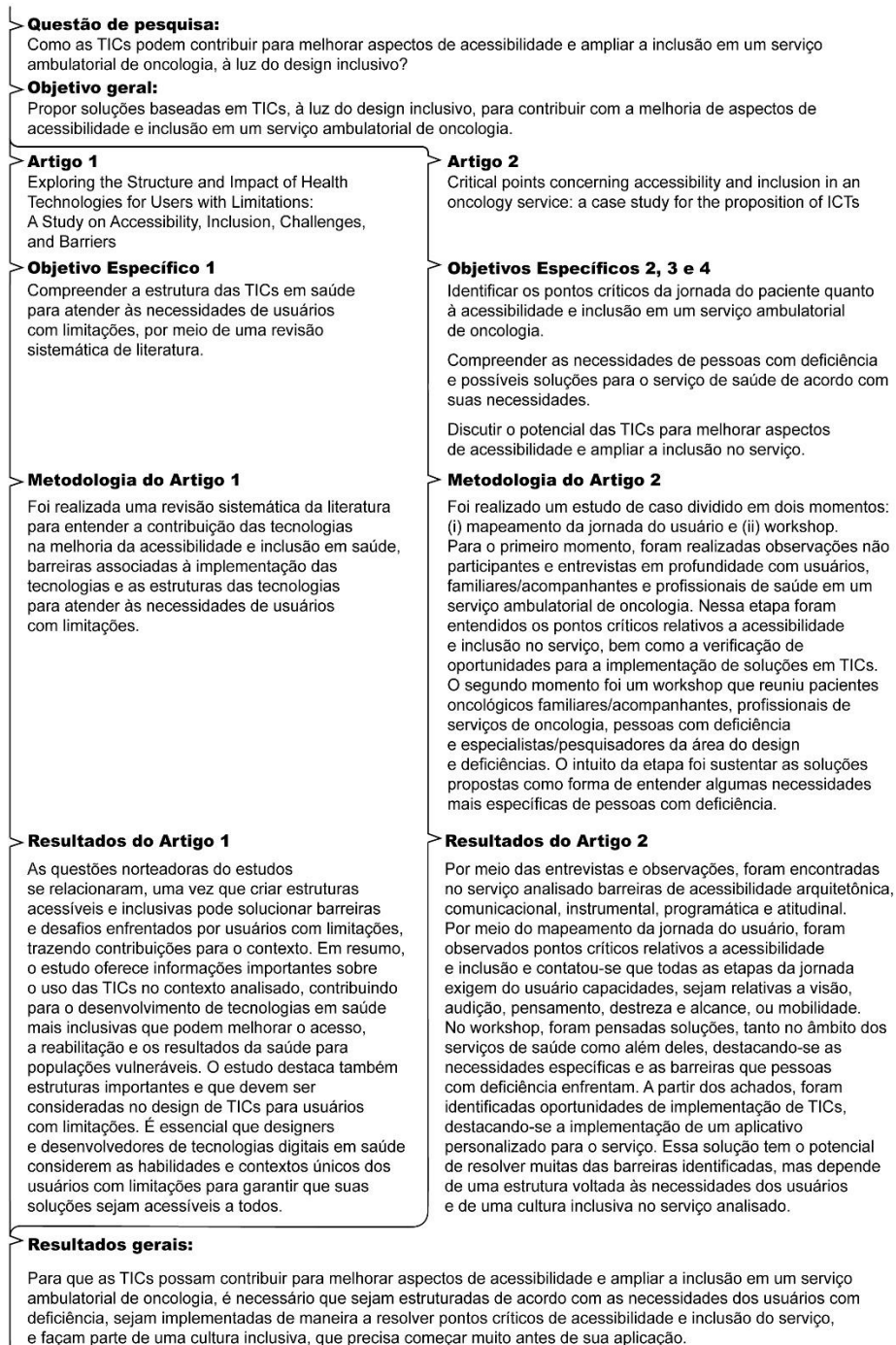
Artigo 1 – Antes de pensarmos em soluções em TICs que auxiliem em aspectos de acessibilidade e inclusão em saúde, é preciso que pensemos em como essas tecnologias precisam estar estruturadas para atender usuários com diversas limitações, sejam elas físicas, cognitivas ou sensoriais. Portanto, esse artigo teve

como objetivo principal compreender, por meio de uma revisão sistemática da literatura, a estrutura das TICs em saúde para atender às necessidades de usuários com limitações. O artigo permitiu a visualização de pontos importantes quando pensamos em tecnologias em um contexto de vulnerabilidades, considerando as doenças crônicas, o envelhecimento e as deficiências.

Artigo 2 – Esse artigo teve como objetivos: (i) a identificação de pontos críticos da jornada do paciente quanto a acessibilidade e inclusão em um serviço ambulatorial de oncologia; (ii) a compreensão das necessidades das pessoas com deficiência e possíveis soluções para o serviço de saúde de acordo com suas necessidades; e (iii) a discussão do potencial das TICs para melhorar aspectos de acessibilidade e ampliar a inclusão no serviço. Para isso, foram realizadas entrevistas em profundidade e observações não participantes com profissionais de saúde, usuários e familiares/acompanhantes em um serviço de oncologia, e um workshop com profissionais de saúde, usuários, familiares/acompanhantes, pessoas com deficiência e especialistas da área do design e deficiências. O artigo trouxe o panorama da jornada dos pacientes pelo serviço, enfatizando as barreiras de acessibilidade encontradas e, dessa forma, discutindo o potencial das TICs como soluções a essas barreiras, com base na literatura de TICs, nos achados das entrevistas e observações, e nas contribuições trazidas no workshop.

Com base nessa estruturação de trabalho, foi elaborado um mapa da dissertação, ilustrado na Figura 1, para melhor visualização e entendimento da proposta.

**Figura 1 - Mapa da dissertação**



### 3 ARTIGO 1

Este artigo foi submetido ao periódico Disability and Rehabilitation: Assistive Technology.

**Explorando a estrutura e o impacto das tecnologias de saúde para usuários com limitações: um estudo sobre acessibilidade, inclusão, desafios e barreiras**

***Exploring the Structure and Impact of Health Technologies for Users with Limitations: A Study on Accessibility, Inclusion, Challenges, and Barriers***

## **Exploring the Structure and Impact of Health Technologies for Users with Limitations: A Study on Accessibility, Inclusion, Challenges, and Barriers**

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## **Exploring the Structure and Impact of Health Technologies for Users with Limitations: A Study on Accessibility, Inclusion, Challenges, and Barriers**

**Purpose:** This article presents a systematic literature review that aims to identify how information and communication technologies (ICTs) in healthcare have been designed to meet the diverse needs of users with limitations.

**Materials and methods:** This study employs a systematic literature review approach and focuses on three research questions: (i) what are the contributions of health technologies to improving accessibility and inclusion in healthcare? (ii) what are the biggest challenges and barriers associated with the implementation of these technologies? and (iii) how are health ICTs structured to meet the needs of users with limitations?

**Results:** We found that a significant proportion of studies focus on the elderly as the target user group, addressing limitations such as memory loss and mobility impairments. Other studies deal with users with cognitive limitations but do not make it the main focus, also including other disabilities. Additionally, some studies have a diverse target user group and aim to observe or compare the adherence of technologies among different groups. The most addressed limitation among the articles was cognitive impairments, followed by mobility, reach and dexterity, vision, and hearing.

**Conclusions:** Our review highlights the importance of ensuring that all health-related technologies are designed with an inclusive approach, involving as many people as possible in the design process to create solutions that are accessible to all, including those with capability losses. We close our study proposing four promising research directions for future investigation.

**Keywords:** ICTs; health technologies; users with limitations; accessibility; inclusion; inclusive design

## Introduction

Approximately 15% of the global population, or 1 billion people, live with a disability, a figure that is expected to increase due to population aging and the rise of chronic diseases [1]. Disabilities can take various forms, including congenital and early onset conditions, and those that arise later in life as a result of chronic diseases or accidents [2]. These different forms of disability can result in the loss of various human capabilities, such as vision, hearing, cognitive functioning, reach and dexterity, and mobility [3].

A variety of studies have shown that people with disabilities (PwD) often face disparities in accessing healthcare [4–7]. Barriers include individual factors, socioeconomic issues, the severity of the disease or disability, physical constraints, inaccessible infrastructure, lack of information, and inadequate care [1,5,8].

Digital health has shown promise in meeting the health needs of PwD [9]. Mobile healthcare, the Internet and other information and communication technologies (ICTs) might be opportunities to improve support and inclusion of users with limitations [10,11]. However, the “digital divide” may create barriers and exclude people who lack digital resources, leading to greater vulnerability [12,13].

While digital health technologies can improve access to healthcare for PwD, it is important to ensure that these technologies are accessible to the diversity of individuals and their unique abilities and contexts [14]. This is in line with the principles of inclusive design, which seeks to involve as many people as possible in the design process and create solutions that are accessible to all, including those with capability losses. It is crucial that all health-related technologies are designed with this inclusive approach to ensure that they can be used by PwD [15,16].

The growing use of technology in healthcare has led to numerous studies focused on developing technology for specific user groups, such as PwD [17], limited mobility [18], the elderly [19], and others facing vulnerabilities and limitations. However, there is a lack of a comprehensive understanding of how technology should be designed to meet the diverse needs of patients. In this paper, we address this gap by conducting a literature review to identify how ICTs in healthcare have been structured to serve users with limitations. The term “limitations” is used in the context of the

barriers that individuals interact with, rather than as an inherent characteristic of the person or body, as disabilities arise from these barriers [20].

The main objective of the study is to understand the structure of health technologies to meet the needs of users with limitations. We aim at clarifying the problem by formulating questions that address the contributions of such technologies, as well as the challenges and barriers encountered during implementation. The study will focus on the questions related to the use of technologies to improve accessibility and inclusion in the health sector, the main challenges and barriers to implement these technologies, and the ways health ICTs are structured to meet the needs of users with limitations.

## **Materials and Methods**

This study employs a systematic literature review approach, following the methodology outlined by Arksey and O'Malley [21], which includes: (i) defining the research questions, (ii) identifying relevant studies, (iii) selecting studies, (iv) extracting data, and (v) synthesising, summarising, and reporting the findings.

### ***Define research questions***

To address the main objective of the study, we formulated specific questions that focus on clarifying a problem related to a particular population [22]. The aim of this study is to understand the structure of health technologies that serve users with limitations, including their contributions as well as challenges and barriers. To achieve this goal, we defined the following guiding questions:

RQ1: What are the contributions of health technologies to improving accessibility and inclusion in healthcare?

RQ2: What are the biggest challenges and barriers associated with the implementation of these technologies?

RQ3: How are health ICTs structured to meet the needs of users with limitations?

### ***Identify relevant studies***

To conduct a comprehensive literature search, we first identified potential keywords and performed preliminary queries in five databases. The alignment of findings with the review goals was verified analysing 5 random articles resulting from the initial search, as recommended by Tortorella et al. [23]. Based on this, we refined the keywords and databases to better match the study's objectives.

The final search query included the following keywords: health\* AND (disab\* OR impair\* OR "mobility reduced") AND ("ICT in health" OR "information and communication technolog\*" OR "digital health"). The search, restricted to abstracts, was carried out in the following seven databases: Scopus, Wiley, Pubmed, Bireme, Embase, ScienceDirect and Web of Science. However, it should be noted that the ScienceDirect database does not allow for the use of asterisks, more than 8 Boolean operators, or searches limited to abstracts. Thus, we conducted a separate search in Science Direct using the keywords health AND ((disability OR disabled) OR (impair OR impairment) OR "mobility reduced") AND ("ICT in health" OR "information and communication technology" OR "digital health"), limited to abstracts, titles, and keywords. The search was conducted in May 2022, and the initial search across all databases yielded a total of 3,132 articles.

### ***Select studies***

To ensure the highest possible quality in the systematic review process, the study selection step was subjected to peer-review by two authors, as recommended by Moher [24]. This step followed the standard Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines, which involves the following steps: identification, screening, eligibility, and inclusion [25].

The inclusion and exclusion criteria defined are outlined in table 1. The identification phase involved inputting the inclusion criteria into the databases' filters or

manual search (depending on the database), resulting in a total of 2,052 articles. During the screening stage, we excluded literature reviews, opinion articles, theoretical essays, meta-analyses, perspectives, commentaries, protocols, editorials/lessons from the field, correspondence articles, congress reports, view/personal points, position papers, and debates, leaving 832 articles for further analysis. We retained articles that reviewed applications in app stores, as they could be relevant to our analysis. After removing 147 duplicates, the triage stage resulted in 685 articles for further analysis.

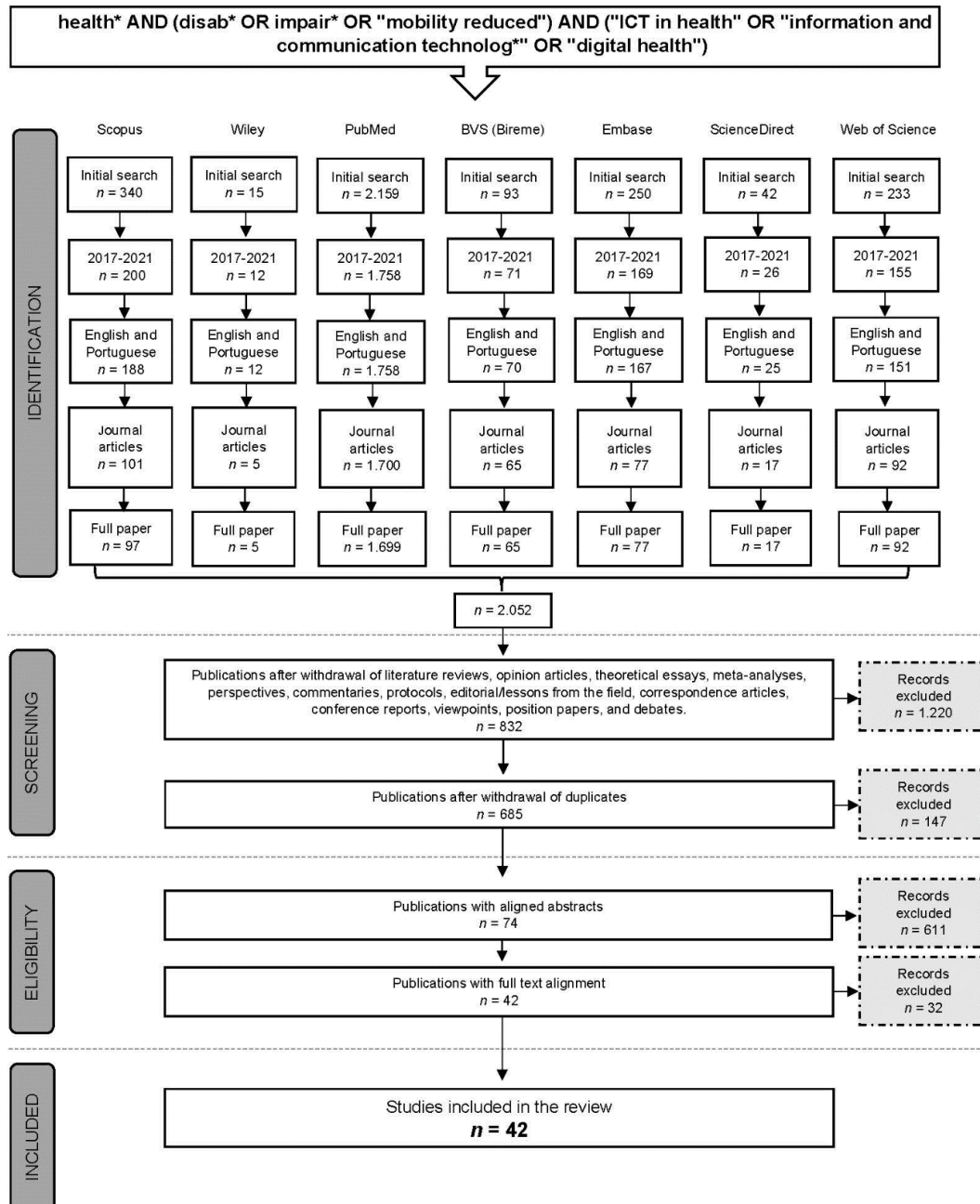
Table 1. Inclusion and exclusion criteria.

Inclusion criteria	Exclusion criteria
Articles published from 2017 to 2021	Literature reviews, opinion articles, theoretical essays, meta-analyses, perspectives, commentaries, protocols, editorials/lessons from the field, correspondence articles, congress reports, view/personal points, position papers, and debates
Articles in English and Portuguese	Duplicate articles
Articles published in journals	Articles not dealing with technologies in a context of accessibility and limitation
Articles published in full	Articles not dealing with the health context Articles not dealing with the context of technologies

The first step of the eligibility stage consisted of reading the abstracts of the 685 articles selected in the triage stage. Were not considered eligible articles that (i) did not deal with technologies in a context of accessibility and limitation; (ii) did not deal with the health context; (iii) did not deal with the context of technologies; (iv) only focused on clinical resolution, not accessibility aspects; (v) although dealing with users with limitations and applying technologies for accessibility, had no relationship with health, illness processes, health services, or health prevention; and (vi) despite dealing with people with limitations based on common understanding (e.g., elderly people), did not bring the limitation as the focus of research and application of technology. We also excluded disability diagnostic articles. Whenever divergence occurred, a third researcher was asked to make the final decision. The second step of the eligibility stage consisted of reading the 74 articles remaining from the first step in full. The

analysis excluded 32 articles that were not aligned with our research focus. A final sample of 42 articles were included in the systematic review. Figure 1 presents a detailed flowchart of the Systematic Literature Review, adapted from the PRISMA model [25].

Figure 1. Selection of studies to be included in the review.



### ***Chart the data***

At this stage, we conducted an initial qualitative analysis of the data from the review articles. The following information were organised in an Excel spreadsheet: title, year of publication, authors, research centres, journal, objective, article's main information, research procedure, theme, target users, identified limitations (related to vision, hearing, thinking, reach and dexterity, and mobility), technologies applied/addressed in the article, structure of technologies to serve users with limitations, technology elements and components, contributions of technologies, implementation challenges/barriers, article results/discussions, relationships with inclusive design, and comments and/or criticisms by the authors.

### ***Collate, summarise and report results***

We start this phase by providing an overview of the studies in terms of the technologies they apply or address, target users and their identified limitations. Next, a thematic analysis is performed [26] to address our guiding research questions. For RQ1 and RQ2, thematic categories were defined following an inductive approach based on the data collected from the articles. For RQ3, we employed both inductive and deductive approaches, drawing from specialised literature to codify the themes identified in the studies [27].

## **Results and Discussion**

### ***Overview of the studies***

An overview of the studies is presented in table 2, which provides initial information for an understanding of the research. The articles in the table are coded by numbers and are referred by them in the following sections.

Table 2. Overview of studies concerning technologies applied/addressed, target users, and their limitations.

Code	Reference	Target users	Limitations	Technologies applied/addressed
[28]	Urban (2017)	Elderly people	Not specified (general context of limitation among the elderly)	Digital health (wearables and health apps in the context of fitness activities) and home monitoring technology for long-term chronic conditions
[29]	Keränen et al. (2017)	Older adults with frailty	Thinking/ Reach and dexterity/ Mobility	Internet or advanced mobile devices (smartphones and tablet)
[30]	Rikard et al. (2018)	Older adults with cognitive impairments residing in continuing care retirement communities	Thinking/ Mobility	Computer and the Internet
[31]	Giunti (2018)	Patients with chronic conditions	Not specified (general context of limitations caused by chronic diseases)	mHealth solutions
[32]	Barlott et al. (2019)	People with intellectual disabilities	Thinking	Mainstream ICTs (mobile phone, computer, Internet, etc.)
[33]	Isernia et al. (2019)	People with Parkinson disease, multiple sclerosis, and stroke	Mobility/ Reach and dexterity/ Thinking	HEAD rehabilitation program (virtual reality platform of telerehabilitation) / (ClinicHEAD and HomeHEAD)
[34]	Park et al. (2019)	Community in general	Not specified (general context of disabilities)	CHSNA system (ICT-based system)
[35]	Chiu and Wu (2019)	Older adults who live in long-term care facilities	Not specified (general context of limitation among the elderly)	Software app LINE (a freeware app for instant communications on electronic devices) and Youtube
[36]	Gibson et al. (2019)	Patients with mild learning disabilities	Thinking	Tablet app for medical consultation with Alternative and Augmentative Communication
[37]	Martin-Hammond et al. (2019)	Older adults	Not specified (general context of limitation among the elderly)	Intelligent assistants
[38]	Marxreiter et al. (2019)	Patients with Parkinson disease	Thinking/ Reach and dexterity/ Mobility	Digital technology and media (computers and smartphones)
[39]	Seifert and Cotten (2020)	Older adults living in long-term care	Not specified (general context of limitation among the elderly)	TV, radio, computers/laptops, smartphones, and tablets
[40]	Contreras-Somoza et al. (2020)	Older adults with mild cognitive impairment	Thinking	EhcoBUTLER (ICT platform)
[41]	Choi et al. (2020)	Older adults with vision impairment	Vision	Internet
[42]	Guzman-Parra et al. (2020)	Older adults with dementia/mild cognitive impairment and their caregivers	Thinking	ICTs in general
[43]	Babatunde et al. (2020)	Individuals with hand and upper limb injuries	Thinking/ Reach and dexterity	Hand Therapy Online Coping Skills (HOCOS) - web-based portal
[44]	Christiansen et al. (2020)	Older adults with cognitive impairment	Thinking	Mobile health (mobile phone, tablet, social media, game applications, etc.)
[45]	Anisha et al. (2020)	Disabled patients	Mobility/ Reach and dexterity/ Thinking	Assistive device for disabled patients
[46]	Debeljak et al. (2020)	Older people with lower limb loss	Mobility	ICTs in general
[47]	Petrescu-Prahova et al. (2020)	Older adults	Not specified (general context of limitation among the elderly)	Digital communication tools
[48]	Najm et al. (2020)	People diagnosed with rheumatic and musculoskeletal diseases	Reach and dexterity/ Mobility	mHealth apps for self-management in rheumatology
[49]	Jakobsson et al. (2020)	Older adults with cognitive impairments	Thinking	Everyday information and communication technologies - ICTs for eHealth use and ICTs for general use

[50]	Ali et al. (2020)	People with disabilities	Not specified (general context of disabilities)	ICT tools for healthcare (computer, mobile phone, tablets, and the Internet) - ICT-enabled healthcare
[51]	LoBuono et al. (2021)	People with Parkinson Disease and their caregivers	Thinking/ Reach and dexterity	Digital health in general
[52]	Rai et al. (2021)	Stroke patients	Not specified (general context of post-stroke limitations)	Blood pressure technology for stroke patients
[53]	Nimmolrat et al. (2021)	Visually impaired users (low vision and blindness)	Vision	This Ru Tan Ya mobile application (smart device was also used with the application in voice-over touch or disability modes)
[54]	Ali et al. (2021)	Elderly persons with disability	Not specified (general context of limitation among the elderly)	eHealth
[55]	Arighi et al. (2021)	Patients with dementia	Thinking	Telemedicine (video calls)
[56]	Bente et al. (2021)	Young people with low educational level, young people with high educational level, young people with intellectual disabilities, migrants, adults and the elderly	Thinking and mobility	CoronaMelder app (contact tracing app for COVID-19)
[57]	Kairy et al. (2021)	Individuals with physical disabilities and with mobility limitations	Mobility	OnRoule App
[58]	Minen et al. (2021)	People with the top five most disabling neuropsychiatric conditions (stroke, migraine, depression, Alzheimer's disease and dementia, and anxiety)	Thinking	Apps for specific neuropsychiatric conditions
[59]	Gagnon Shaigetz et al. (2021)	Patients with cognitive impairments	Thinking	bWell cognitive care platform with immersive virtual reality
[60]	Ferguson et al. (2021)	First-time hearing aid users (hearing loss patients)	Hearing	m2Hear (m-health educational programme)
[61]	Blacklow et al. (2021)	Not specified. People with limitations in general or in a vulnerable situation (including social vulnerability)	Not specified (general context of disabilities)	COVID-19 contact tracing apps
[62]	Tiersen et al. (2021)	People with dementia and their caregivers	Thinking	Intelligent assistive technologies for dementia
[63]	Biehl et al. (2021)	Older persons in need of support	Not specified (general context of limitation among the elderly)	Web-based community-based healthcare services for older persons in need of support
[64]	Penev et al. (2021)	Children diagnosed with autism spectrum disorder	Thinking	GuessWhat mobile application
[65]	Layton et al. (2021)	Assistive technology users (older people and people with disability in general)	Not specified (general context of limitation among the elderly and disabled)	Assistive technologies/ digital technologies
[66]	Branco et al. (2021)	Individuals with Locked-in syndrome	Reach and dexterity/ Mobility	Assistive Technologies / Brain-Computer Interfaces
[67]	Meyer et al. (2021)	Adults with hearing impairment	Hearing	eHealth
[68]	Shareef et al. (2021)	Elderly and disabled people	Not specified (general context of limitation among the elderly and disabled)	Machine Intelligence: autonomous homecare system governed by ambient intelligence
[69]	Dai and Hu (2021)	People with disabilities	Thinking/ Hearing/ Vision/ Mobility	ICT-powered DSN: WeChat (ICT program from China)

In 18 of the 42 articles analysed, the elderly are the predominant target users. Studies either focus on elderly users with specific limitations [29,30,40-42,44,46,49,56], or on elderly users with general limitations such as memory loss, mobility impairments, and limitations caused by chronic diseases [28,35,37,39,47,54,63,65,68]. According to the United Nations, over 46% of elderly people in the world have some form of disability, which makes them more vulnerable in society [70]. Technologies have been seen as a way to improve their lives and overcome the barriers they face [71].

Other groups of users included in the studies displayed various conditions, predominantly cognitive impairments [32,36,55,56,58,59,62,64]. Other articles dealt with users with limitations related to cognitive aspects, but not as the main focus [69]. Giunti [31] targeted at patients with chronic diseases, which may cause a range of limitations and vulnerabilities [1]. Furthermore, some studies had diverse target users [58,61], which aimed to observe or compare technology adherence among different groups.

Regarding the limitations faced by users, it was found that a significant number of 14 studies did not specify the exact nature of these limitations. Despite dealing with various contexts of limitation, such as age [28], chronic conditions [31], disabilities [50], or other general societal conditions [34], the specific limitations were not clearly outlined. Of the remaining studies, 11 focused on multiple limitations within the same [38] or different groups of users [56], while 17 focused on a single limitation. As previously mentioned, the most commonly addressed limitation were cognitive impairment and mobility (10 studies each), followed by reach and dexterity (8 studies), and vision and hearing (3 studies each).

In terms of technologies, 12 articles investigated, applied or analysed the use of general ICTs by users with limitations [29,30,32,38,39,41,42,44,46,47,49,50]. These technologies are not specifically designed to meet the needs of users with limitations but are instead available for anyone to use, such as computers, smartphones, tablets, digital media, games, and applications. None of these devices or applications have specific configurations designed for target users or health treatment. The purpose of

these studies is to understand how individuals with limitations adhere to commonly disseminated technologies. For instance, Barlott et al. [32] investigate the experiences of users with intellectual disabilities using mainstream ICTs, aiming to determine whether these technologies foster social connection with others. Similarly, 4 articles examined general health technologies using the same logic as the previous studies [31,51,54,67]. For example, Ali et al. [54] investigate the factors that influence elderly individuals with disabilities in their decision to use health technologies or not.

Remaining studies have investigated the use of various health technologies to support users with limitations. For example, wearable technologies [28], health applications [28,35,36,48,53,56-58,61,64], virtual reality applied to health [33,59], artificial intelligence applied to health [37,53,62,68], digital devices for pressure measurement [52], online hand therapy portal [43], telemedicine by video calls [55], assistive technologies [62,65,66] brain-computer interfaces [66], ICT-based systems [34], ICT platforms [40,60,69], web-based services [63], and home-based monitoring technologies [28].

***RQ1: What are the contributions of health technologies to improving accessibility and inclusion in healthcare?***

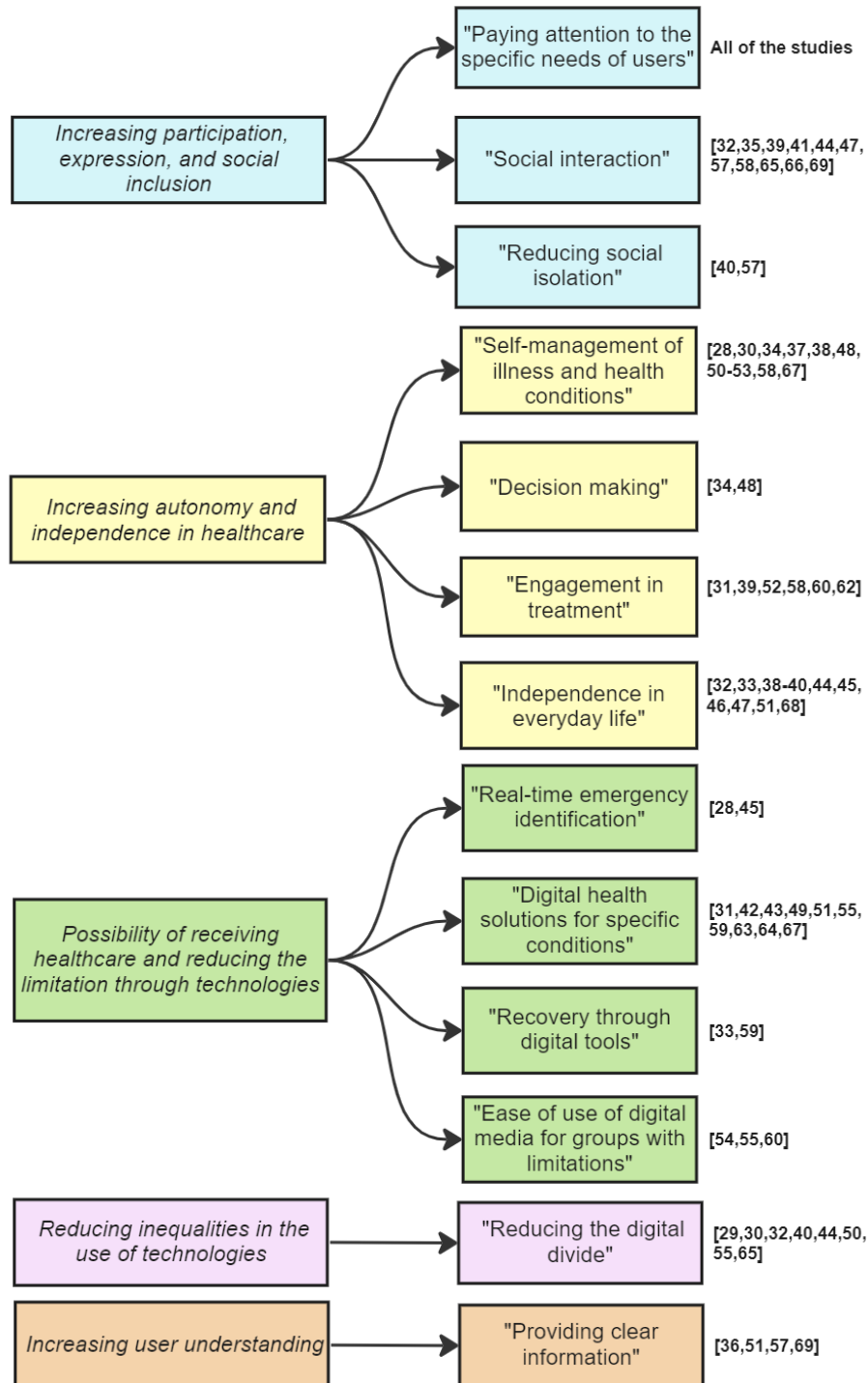
Regarding contributions of technology to accessibility and inclusion, five main themes emerged, with some studies presenting more than one thematic axis. The most frequently occurring theme was increasing participation, expression, and social inclusion, which was present in all studies. Additionally, 24 studies highlighted the potential of technology to increase autonomy and independence in healthcare, while 15 studies explored the possibility of receiving healthcare and reducing limitations through the use of technology. Eight studies focused on reducing inequalities in the use of technologies, while 4 studies emphasised the importance of increasing user understanding. Figure 2 presents a detailed overview of the themes and sub-themes related to the contributions of technology to accessibility and inclusion found in each study.

On the theme of *increasing participation, expression, and social inclusion*, the

following three sub-themes emerged: (i) “paying attention to the specific needs of users”, (ii) “social interaction”, and (iii) “reducing social isolation”. Sub-theme (i) was present in all studies through the proposition or discussion of technologies best suitable for the needs of users with limitations. Even papers that reviewed applications, such as Blacklow et al. [61] on Covid-19 contact tracing apps, emphasise the importance of inclusive design to accommodate population diversity and specific needs. Sub-theme (ii) revealed that individuals with limitations and vulnerability in society could benefit from inclusive technology. For example, Dai and Hu [69] developed an application as part of a Chinese plan to promote the inclusion of users with disabilities during the pandemic, aiming to improve their participation in several aspects of social life. Additionally, Branco et al. [66] show that individuals with locked-in syndrome could use brain-computer interfaces to express themselves and control their environment, such as turning off lights, controlling wheelchairs, and opening doors. Finally, sub-theme (iii) highlighted how users with disabilities often experience isolation in society. For example, Contreras-Somoza et al. [40] propose an ICT platform to include elderly people with mild cognitive impairment, who are sometimes disconnected from their communities.

On the theme of *increasing autonomy and independence in healthcare*, the studies reviewed revealed four sub-themes: (i) “self-management of illness and health conditions”, (ii) “decision making”, (iii) “engagement in treatment”, and (iv) “independence in everyday life”. The related contributions are particularly relevant as they empower vulnerable users with limitations to take care of their own health and participate in their healthcare process. Digital media provides these users with the opportunity to be in control of their care and to engage in joint decision-making with the healthcare team. Najm et al. [48] discuss health applications for managing rheumatology, emphasizing the need for users to self-manage their symptoms and assume a leading role in their condition. LoBuono et al. [51] highlight the benefits of digital health technologies for people with Parkinson's disease, enabling them to search for information and maintain their independence. Anisha et al. [45] propose an assistive technology for remote monitoring of patients with disabilities, enabling them to be monitored without the physical presence of a doctor and giving them more

Figure 2. Thematic map of health technology contributions to accessibility and inclusion.



independence in their daily lives, relying on the physicians' presence only for emergency events.

Research papers on the theme of *possibility of receiving healthcare and reducing the limitation through technologies* revealed four sub-themes: (i) "real-time emergency identification", (ii) "digital health solutions for specific conditions", (iii) "recovery through digital tools", and (iv) "ease of use of digital media for groups with limitations". These sub-themes all relate to the potential of digital health to benefit users with limitations. For example, monitoring technologies can identify emergencies in real time, as demonstrated by Urban's [28] study with the elderly. Digital health tools can also help improve limiting conditions or other health situations, such as the use of mobile phones and tablets to aid the memory of older adults with dementia/mild cognitive impairments, as found by Guzman-Parra et al. [42]. Additionally, technology can provide rehabilitation for diseases, as shown in Isernia et al.'s [33] clinical trial of a virtual rehabilitation program based on virtual reality, which was effective in the functional recovery of patients with Parkinson's disease, multiple sclerosis and stroke. Finally, digital media can make it easier for users with limitations to solve problems, as exemplified by Ferguson et al.'s [60] proposed technological intervention to optimise hearing aid use, which increases accessibility by overcoming geographic and mobility barriers. In this study, users benefit from technology as they do not need to leave their home or the environment they are in. This aspect was also highlighted by Ali et al.'s [54] investigation into factors influencing the use of technology among elderly users with limitations.

Regarding the theme of *reducing inequalities in the use of technologies*, only one sub-theme was identified: "reducing the digital divide". Several articles address the issue of unequal access to and ability to use technologies among different groups and suggest addressing this problem through the development of technologies that are adaptable to specific limitations. Keränen et al. [29] discuss the differences in technology perception among non-frail, pre-frail, and frail elderly, and highlight that differences can be attributed to age and the prevalence of visual or cognitive disorders. The authors stress the importance of designing technology solutions that minimise the growing digital divide in society, with a focus on population diversity rather than social

exclusion.

Finally, regarding the topic of *increasing user understanding*, the only sub-theme identified was “providing clear information”. This contribution enables people with limitations to understand the technology they are using, the content provided, and their health situation through digital media. Gibson et al. [36] highlight the importance of clear information in their study, which assessed the feasibility of using tablet technologies to promote communication between general practitioners and patients with mild learning disabilities. The study found that the use of an application designed for the needs of this patient group increased user understanding of the various possibilities of interacting with the application (text, audio or image) and to communicate with the medical team.

In the context of promoting accessibility and inclusion, it is evident that all the thematic axes are interconnected. The studies reviewed in this paper contribute to expanding opportunities and possibilities for people who experience limitations related to social or digital inclusion, autonomy, information, healthcare, or other restrictive conditions. These contributions have led to the enhancement of the user groups analysed, either through the implementation of technology or through the discussion of future directions. That is aligned with Duplaga’s [11] view of ICTs to increase support and inclusion in contexts of limitation while reducing disparities in their use. However, while inclusive design aims to cater to all individuals in the design of solutions [15], most studies only consider a specific user group. This approach may overlook the fact that people with one limitation often have other associated limitations, underscoring the need for customised technology solutions more favourable to the specific needs of a group of users.

***RQ2: What are the biggest challenges and barriers associated with the implementation of these technologies?***

Out of the 42 articles analysed, 35 discussed challenges and barriers in implementing technologies for users with limitations. A single main thematic category was identified: *difficulty in using/discontinued use/non-use of technologies*, i.e.,

barriers evidenced in the non-use of technologies, interruption of use or difficulty in managing them. 12 sub-themes emerged from the analysis, with the most common being limitation linked to a possible lack of accessibility (21 articles). Other sub-themes and associated articles are presented in table 3.

Table 3. Organisation of themes and sub-themes in the analysis of challenges and barriers related to implementing technologies.

Main thematic axis	Sub-themes	Categorisation within sub-themes	Studies
<i>Difficulty in using/ Discontinued use/ Non-use of technologies</i>	"Limitation linked to a possible lack of accessibility"	-	[28-30,34-36,38,41,42,44,46,49-52,54,56,57,58,65,69]
	"Lack of experience with/knowledge about"	Technologies	[28,39,40,42,44,49,53,55,63]
		Health information	[37,51-53]
	"Characteristics or technical problems of the technologies"	-	[33,37,48,58,60,63,64,66]
	"Distrust/uncertainty"	Reliability of technologies in providing health information	[41,58]
		Data privacy and security concerns	[28,37,44,48,58,63]
		Uncertainty with technologies in general	[68]
	"Lack of interest about the usefulness of the technology"	-	[41,44,48,49,52]
	"Lack of clear and organised information"	Use of the technology	[52,60,64,65]
		Purpose of the intervention	[52]
	"Need for internet"	Need of internet to use the technology	[37,63]
		Internet connection problems	[62,64]
	"Socioeconomic barriers"	-	[41,50,63]
	"Dependence on others"	-	[32,52]
	"Geographic barriers"	-	[50,54]
	"Social isolation"	-	[29,62]
Lack of technical support"	-	[62]	

Among the sub-themes identified in the analysis, “limitation linked to a possible lack of accessibility was the most frequent”. That reveals the lack of a holistic, in-depth analysis in several studies dealing with health technologies for users with limitations. For instance, Urban [28] studies the applications of digital technologies for the elderly but excluded from the analysis those who had no prior contact with technology, impairing the generalisation of findings. Likewise, Rikard et al. [30] analyse the discontinuity in the use of general technologies (computer and internet) by older adults residing in continuing care retirement communities. Assuming that general technologies are not designed for the wide existing diversity, these users have discontinued their use, precisely because of the limitation arising from age together with the lack of accessibility of technologies for the specific characteristics of this group.

On the sub-theme of “lack of experience/knowledge”, Seifert and Cotten [39] argue that many elderly individuals do not use modern technologies (e.g., tablets and smartphones) due to a lack of experience with them. Similarly, Martin-Hammond et al. [37] highlight the difficulty older adults face in understanding medical jargon in intelligent assistants for their health. The sub-theme of “characteristics or technical problems of the technologies” was also identified as a barrier. Najm et al. [48] found that the delay in loading information into an app for self-management of rheumatology and the time lost in the process presented a challenge for patients. The sub-theme of “lack of interest about the usefulness of the technology” was observed in the study by Christiansen et al. [44], where many elderly individuals with cognitive impairment did not see the technologies as necessary for their lives and preferred using paper in daily routine (e.g., regular paper calendar instead of digital one). However, such lack of interest may stem from the limited accessibility of technology for older adults and their deficit of experience and knowledge, highlighting the interconnection among barriers.

The sub-theme of “distrust/uncertainty” was identified as a barrier to the implementation of technologies, which was due to the lack of reliability of technologies in providing health information [41], concern with data privacy and security [37] and uncertainty with technologies in general [68]. “Lack of clear and organised information”, another sub-theme, was related to the lack of information on how to use the technology and the purpose of the intervention. Penev et al. [64] found that children with autism

struggled to interpret game instructions, while stroke patients struggled to understand the purpose of pressure control intervention performed digitally, as observed by Rai et al. [52]. Additionally, the “need for internet” was identified as a determining factor in technology use, as many technologies require internet connectivity to operate, as in the study by Biehl et al. [63], or because internet connection problems harm technology use, as discussed by Tiersen et al. [62].

Although having a lower recurrence in the studies, some sub-themes are equally important in the analysis of barriers to the implementation of technologies in healthcare. “Socioeconomic barriers”, for instance, were evidenced in only 3 of the studies but are extremely relevant for vulnerable populations. Choi et al. [41] show that older adults with visual impairments, who may have low income linked to health problems and disability, are less likely to use technologies due to the costs of internet subscription and equipment, which makes them even more vulnerable. “Geographic barriers” are also significant, with people with disabilities in remote areas using fewer health ICTs [50]. “Dependence on others” was also identified as a barrier. Barlott et al. [32] identified that the management of technologies by patients with intellectual disability is supervised by family members, decreasing their engagement. “Social isolation” and “lack of technical support” were also identified as challenges. Tiersen et al. [62] found both sub-themes present and related due to Covid-19. Patients with dementia, who could benefit from technologies, were isolated and unable to understand why technology was used. This factor was exacerbated by the lack of technical support and training for patients, hampered by social distancing.

While health technologies have the potential to improve healthcare, there are still limitations that suggest the solutions are not fully inclusive for all. Bente et al. [56], for example, focus on a Covid-19 app for all people, but only tested it with elderly and young people with intellectual disabilities, ignoring the existing diversity in the population. This limitation was also identified in other studies and is complex, as different people have different needs and therefore require different solutions [72].

### **RQ3: How are health ICTs structured to meet the needs of users with limitations?**

To guide the analysis related to RQ3, we used the accessibility fundamentals recommended by the Web Accessibility Initiative [73] as a starting point, but we also considered empirical categories that emerged from information in the articles. Among the 42 articles reviewed, 41 provided insights on how technologies could be better structured to support users with limitations; only the study by Debeljak et al. [46] did not address this issue. Table 4 presents the organisation of themes and related articles. We found that most studies address multiple thematic axes simultaneously, reflecting the complexity of the topic.

Table 4. Organisation of themes and sub-themes identified in the analysis of ICT structures to meet the needs of users with limitations.<sup>2</sup>

<b>Themes and sub-themes based on the Web Accessibility Initiative [73]</b>	<b>Studies</b>
<i>Operable user interface and navigation</i>	
“Functionality is available from a keyboard”	[35,48,53]
“Users have enough time to read and use the content”	[62]
“Content does not cause seizures and physical reactions”	None
“Users can easily navigate, find content, and determine where they are”	[29,33-37,40,43,47,48,51-53,57,60,63,68,69]
“Users can use different input modalities beyond keyboard”	[32,36,45,53,57,63,66]
<i>Perceivable information and user interface</i>	
“Text alternatives for non-text content”	[36,61]
“Captions and other alternatives for multimedia”	[41,69]
“Content can be presented in different ways”	[28,32,34,36,41,43,47,48,52,56,57,59,61]
“Content is easier to see and hear”	[28,34,36,41,43,47,57]
<i>Understandable information and user interface</i>	
“Text is readable and understandable”	[34,36,37,56,57,60,62]
“Content appears and operates in predictable ways”	None
“Users are helped to avoid and correct mistakes”	[36,53,61,62]

<i>Robust content and reliable interpretation</i>	
“Content is compatible with current and future user tools”	[43]
<b>Themes and subthemes based on empirical categories that emerged from the analysis</b>	<b><sup>2</sup>Studies</b>
<i>Custom technologies</i>	
“Technologies adapted to individual needs”	[28,30,32,34,36,37,38,42,44,45,47-50,52,53,57,59-61,63,65,69]
<i>Training</i>	
“Education for the use of technologies”	[30,32,38-41,44,49,50-52,54,60,62,63,67]
“Technical support during the use of the technology”	[33,44,63]
Specific tutorials for the use of a technology	[43,59,63]
<i>Use of design approaches</i>	
“User involvement in prototyping or improving technologies”	[31,47,48,53,56,57,60]
“Multi-stakeholder involvement in prototyping and improving technologies”	[31,62]
“User-centered design”	[31,34,40,53,57,59,62,63,67]
<i>Inclusion of others in the technology implementation process</i>	
“Family members or caregivers”	[32,40,45,47,52,55,64]
“Health professionals”	[28,56]
<i>Playful design</i>	
“Gamification”	[31,33,58,59,64]
“Other attractive resources for the use of technologies”	[32,33,35,37,40,58,64]
<i>Privacy guarantee</i>	
“Data security”	[28,37,44,47,48,57,58,63]

The analysis of each thematic category will follow a logical order of the

<sup>2</sup> ICT structures to meet the needs of users with limitations generated a model, which derived from the findings of this systematic review of the literature, but which is part of a separate article submitted to a conference. This model and its explanations can be found in Appendix 1 of this article.

relationships between themes. The first thematic category is *custom technologies*, with the sub-theme “technologies adapted to individual needs” identified in 23 studies. It highlights that for a technology to serve users with limitations, it needs to be customizable to meet specific needs, i.e., present features that enable anyone to use it. For example, Gagnon Shaigetz et al. [59] emphasise personalisation as a fundamental structure by introducing customizable exercises on a virtual reality platform for patients with cognitive impairments. The user can set the platform to play standing or sitting, which increases the range of possibilities for use. This technology allows for the user’s inclusion, as it also allows for embodiment through a self-avatar customizable according to the user’s identification. While this thematic category is broad, others provide more specific and focused approaches to how technologies can be customised to meet limitations.

One theme that emerged in 14 studies is *perceivable information and user interface*. Within this theme, there are several sub-themes identified in the studies. Two of them presented the sub-theme of “text alternatives for non-text content”, which refers to the need for technologies to present inclusive text alternatives to describe images, videos, and other non-text content. For example, Gibson et al. [36] note that although images can be beneficial for patients with learning disabilities, many may not understand the meaning behind the image without a text alternative. Another sub-theme identified in two studies was “captions and other alternatives for multimedia content”, such as videos, to make them accessible for deaf, blind, and other individuals with disabilities. Dai and Hu [69] highlight the importance of including sign language and screen-readable text for technologies to be inclusive. The sub-theme “content can be presented in different ways” was identified in most of the articles within this thematic category, with 13 studies addressing the issue. This sub-theme included the possibility of increasing font size, using image resources combined with text, and choosing the presentation of content, whether spoken or written. For example, users with intellectual disabilities may find audible information easier than texts [32], while small icons are difficult for older people to see and click [28]. In both cases, allowing the content to be presented in different forms enhances accessibility and inclusion. Finally, the sub-theme of “making content easier to see and hear” was identified in 7 articles. The sub-

theme includes the option of changing colours, resizing images, increasing and decreasing audios without compromising content and adding the possibility of pausing them as needed. For instance, Babatunde et al. [43] suggest placing white spaces around the text and using a simple colour scheme to enhance readability.

The theme of *operable user interface and navigation* is another area of concern for creating technology structures for users with limitations, which was found in 22 articles. This theme includes five sub-topics, with only four being identified: (i) “functionality is available from a keyboard” (3 articles), (ii) “users have enough time to read and use the content” (1), (iii) “users can easily navigate, find content, and determine where they are” (18), and (iv) “users can use different input modalities beyond keyboard” (7). Subtheme (i) is exemplified by Najm et al. [48], where apps for self-management of rheumatology were made available on tablets, with keyboard-enabled use, helping patients with finger pain to navigate the app with ease. Sub-theme (ii) is about respecting the users’ timing and allowing them to use the technology at their own pace. That motivated patients with dementia to use smart home technologies in the study by Tiersen et al. [62]. Sub-theme (iii) concerns ease of use and user-friendly technologies. In the articles where this sub-theme was identified, technologies were structured in a simple way with content organisation, making it easier for users to navigate and find relevant information. The study by Gibson et al. [36] emphasises that the user interface should have fewer steps, making it more accessible for users with mild learning disabilities. Sub-theme (iv) concerns various input options beyond the keyboard, such as voice recognition and gestures, which facilitate access for people with disabilities. Anisha et al. [45] exemplify this by enabling hand gestures as a way to communicate with technology through sensors programmed to understand each movement.

The theme of *understandable information and user interface*, identified in 9 articles, also brought specificities in terms of ICT structures. Two of the three sub-themes within this category were found in our sample of papers: (i) “text is readable and understandable”, and (ii) “users are helped to avoid and correct mistakes”. Sub-theme (i) emphasises the importance of ensuring that everyone understands the information provided by technologies through simplified language and reduced amount

of texts. For instance, Gibson et al. [36] identify that using medical jargon in technologies hinders patients with mild learning disabilities from understanding the content. Sub-theme (ii) concerns ICTs that provide error messages, usage instructions, and usage feedback to aid users in avoiding and correcting mistakes. As an example, Nimmolrat et al. [53] found that error prevention notifications can help visually impaired users navigate an application, thus preventing confusion.

Lastly, the theme of *robust content and reliable interpretation* with its respective sub-theme “content is compatible with current and future user tools” was found in only one article [43]. The study suggests that to be accessible, ICTs must be compatible with different browsers; otherwise, many users would be excluded from using them.

Other themes that are important in directing technologies for users with limitations were identified in our sample of articles. Some do not have direct connection with accessibility aspects but may be decisive for users to adopt a given technology. One such sub-topic was “data security”, which was identified in 8 studies under the broader theme of *privacy guarantee*. For example, Kairy et al. [57] found that individuals with physical disabilities and mobility limitations were concerned about the confidentiality of data deposited in a social inclusion application. *Inclusion of others in the technology implementation process* was also a thematic category identified in 9 studies. Some studies have shown the importance of including “family members or caregivers” (7 studies) or “health professionals” (2 studies) in the implementation of technology for users with limitations, highlighting the importance of predicting all possible users when structuring the technology. While Petrescu-Prahova et al. [47] found that acceptance of technology by elderly users depends on its adoption by family and friends, Barlott et al. [32] cautions against dependence on others. Thus, it is important to find a balance between involving others in the use of technology and ensuring that target users can use it independently.

Many articles also showed that ICTs should be structured through *playful design*, a thematic category identified in 9 articles, along with its sub-themes “gamification” and “other attractive resources for the use of technologies”. Penev et al.’s [64] study, for example, found that gamification in a mobile application, including reminder and reward systems, was useful for interacting with autistic children, who

benefited from the game-like therapeutic approach. Similarly, Chiu and Wu [35] shows that resources such as Youtube can be valuable for older adults living in long-term care facilities, as listening to and singing old songs helped them recall happy memories and improve their mood, memory, and cognition. Playful design is particularly relevant for ICTs intended for individuals with cognitive limitations; 6 of the 9 articles addressing this theme focused on them. This finding is supported by Koivisto and Malik's [74] systematic review of gamification for older adults, which highlighted that most of the reviewed studies focused on cognitive health of the elderly.

Another theme present in 13 articles was the *use of design approaches*. Many studies suggested design approaches as essential in the prototyping and implementation of inclusive technologies. "User involvement in prototyping or improving technologies" emerged as a sub-theme in 7 of the studies, with Najm et al. [48] emphasizing the value of incorporating patient feedback to create user-friendly applications. In 2 articles, "multi-stakeholder involvement in prototyping and improving technologies" was identified as a sub-theme, with Giunti [31] highlighting the importance of involving healthcare providers in the design of ICTs. Additionally, 9 articles emphasised the use of a "user-centered design" approach when creating technologies for individuals with limitations. Kairy et al. [57] highlights the emerging concept of user-centered design in accessibility, while König et al. [75] stress the relationships between accessibility, inclusion, inclusive design and user-centered design, stating that user involvement in the process of developing a solution is what ensures that their needs are effectively met.

The last theme, identified in 19 articles, is related to *training*. These studies stressed that without adequate education and training, ICTs become redundant, creating a digital divide between those who are familiar with digital technologies and those who are not, particularly among those who are vulnerable due to disabilities [12,13]. Three sub-themes were identified under the broader theme of training: (i) "education for the use of technologies" (16 articles), (ii) "technical support during the use of the technology" (3), and (iii) "specific tutorials for the use of a technology" (3). Sub-theme (i) concerns education for the use of technologies in general or targeted at a specific technology. For example, Jakobsson et al. [49] recommend a joint effort

between health professionals educating older adults with cognitive impairments about the use of technologies and IT assistants making home visits to adapt technologies to the user's environment. Sub-theme (ii) refers to the availability of technical support during use as proposed by Isernia et al. [33], who envisioned a help-desk service to assist users of a rehabilitation program for people with Parkinson disease, Multiple Sclerosis and Stroke. Sub-theme (iii) is related to structured technologies with usage tutorials for troubleshooting, as in Gagnon Shaigetz et al. [59], who propose a tutorial mode on their virtual reality platform for patients with cognitive impairments to ensure that participants started the rehabilitation exercises with comparable levels of familiarity with the actions required to complete them. In summary, articles associated with this thematic category highlight that training and education are essential components in enabling individuals with disabilities to benefit from ICT structures, which is aligned with the digital divide literature [76,77].

### **Future Research Agenda**

This review has significant implications for future research, and we have identified four promising research directions that could be prioritised in a future research agenda.

#### ***Fostering inclusivity in technological advancement by addressing disability-specific needs in the design process***

Despite the existence of several studies demonstrating the use of inclusive design in the development of solutions for people with different characteristics and needs [78,79] and the approach of this study, to the best of our knowledge, no literature reviews have focused on the requirements of specific disabilities. While some studies have explored the use of technology for people with particular limitations, such as cognitive impairments [55,59], there is a lack of in-depth reviews that gather technology requirements for specific groups of users with disabilities. This gap in the literature is concerning since accessibility features designed for one group of users may cause

problems for another group [80] within the broad scope of inclusive design studies.

To advance the field of inclusive design, it is crucial for future research to review the structures of technologies for specific disabilities by delimiting the scope. Such reviews should explore each disability in detail, considering that the requirements of people with different limitations can vary. Identifying commonalities and designing technologies that meet specific needs would be significant. However, it is equally essential to explore all disabilities in-depth to ensure that new technologies are accessible to all, in line with the precepts of inclusive design. By gaining a deep and specific understanding of the needs of each disability, designers can develop technologies with meticulous attention to the differences that may exist among them.

### ***Fostering representation in the design of inclusive technological solutions by addressing different socioeconomic and ethnic contexts in research***

Understanding socioeconomic and ethnic data is essential in reducing disparities and implementing effective health solutions [81]. The social determinants of health refer to factors that influence people's health, and socioeconomic and ethnic issues play a crucial role in determining the individual health outcomes of the population. As such, economic situation, education, protection, and social inclusion differ from region to region [82]. While the state-of-the-art in the design of technologies has predominantly focused on privileged socioeconomic realities, such as those reported by Urban [28], Bente et al. [56], and Kairy et al. [57], it is essential to recognise that the use of technologies varies among people of different income and educational levels [83]. Therefore, it is key to consider people's perspectives about technologies in a social, historical, and cultural context, as emphasised by Foley and Ferri [80]. That becomes even more critical when dealing with a user group that presents more vulnerabilities, such as people with disabilities.

Given the diversity of structures and propositions that work in one reality may not work in another, it is important to direct future research efforts towards studying technologies for users with limitations in countries with undeveloped socioeconomic conditions. When considered in a context of economic and social vulnerability,

conditions of accessibility and inclusion become even more complex and difficult to solve. Therefore, studies comparing the requirements of users with limitations living in different places within different health systems could provide valuable insights for designing technologies that consider diversity and meet the needs of those individuals.

### ***Applying codesign principles in the development of technologies for users with limitations***

Research on technologies for users with limitations has often been based on the perceptions of non-disabled people [84]. The study by Giunti [31], for example, proposes a conceptual model for technologies aimed at users with chronic conditions that is never tested in practice. It is noticed that users are not consulted or brought closer to the technology design project. However, the systematic review by Garcia Carrizosa et al. [85] emphasises that the effective design of technologies for users with limitations must involve the user in the development process.

If users are distanced from technology design by only considering their past experiences of use indirectly, the resulting outputs may not meet their specific requirements and limitations. Users' acceptance may increase when they use technologies designed to accommodate their limitations and participate actively in the design process. Therefore, a promising research direction is one that applies codesign principles in the development of technologies aimed at people with limitations and disabilities.

### ***Fostering the 2030 Agenda through projects that relate ICTs for users with limitations with sustainable environments***

The COVID-19 pandemic has accelerated research on technologies for users with limitations, driven by the digital divide created by the need for remote healthcare [86]. Bridging this divide and implementing inclusive solutions is crucial for achieving the United Nations' (UN) Sustainable Development Goals (SDGs), particularly SDG 3 (good health and well-being) and SDG 10 (reduced inequalities) [87]. While the UN

Agenda 2030 aims to promote improvements that align with the people, planet, prosperity, peace, and partnership principles [88], none of the 42 articles reviewed in this systematic review draws parallels between human and planetary health. Bohn et al.'s [89] systematic review supports this finding by noting that most design articles in the health domain did not establish links with planetary health.

Future proposals should investigate the impact of designing technologies for users with limitations from the perspectives of both human and planetary health. Sustainable design research must involve various stakeholders and consider the diverse goals required for global sustainable development. Design solutions can be more effective when human issues such as health, inclusion, accessibility, equity, well-being, experience, innovation, and inequalities are considered alongside critical themes relevant to planetary health, such as pollution, climate change, and ecosystem sustainability.

## **Conclusions**

This literature review highlights the potential of digital health technologies to meet the needs of users with limitations. However, the shift from in-person to online healthcare has created a digital divide that may exclude such users. Therefore, inclusive design, which entails creating solutions that are accessible to everyone, is crucial to ensure that digital health technologies can be used by all. The objective of this study was to understand the structure of health technologies that serve users with limitations. Through a systematic literature review, the study identified the main limitations addressed by the articles as cognitive impairments, mobility, reach and dexterity, vision, and hearing. Results were examined through the overview of the studies and by answering the three guiding research questions related to the contributions, challenges, and structures of ICTs for users with limitations.

Our review revealed that a considerable proportion of the 42 articles in our corpus concentrate on the elderly as the target user group, with 18 studies specifically addressing their limitations. However, 14 out of 42 studies did not explicitly specify the limitations they addressed. Twelve of the 42 articles examined the use of general ICTs

by individuals with limitations, such as the internet, computers, smartphones, and tablets, offering a general view of their experiences. However, from the perspective of offering accessible usage, looking at the needs of specific groups, these studies do not propose and implement solutions, being restricted to raising questions and future projections. This review emphasises the need for further research to better understand how health technologies can be designed to meet the diverse needs of patients, including those with limitations.

We found an interdependence between this study's guiding questions, as creating accessible and inclusive structures can solve barriers and challenges faced by users with limitations, leading to contributions to the context. In summary, this study offers valuable insights into the use of ICTs in healthcare for users with limitations, contributing to the development of more inclusive health technologies that can enhance healthcare access, rehabilitation, and outcomes for vulnerable populations. It is essential for designers and developers of digital health technologies to consider the unique abilities and contexts of users with limitations to ensure that their solutions are accessible to all.

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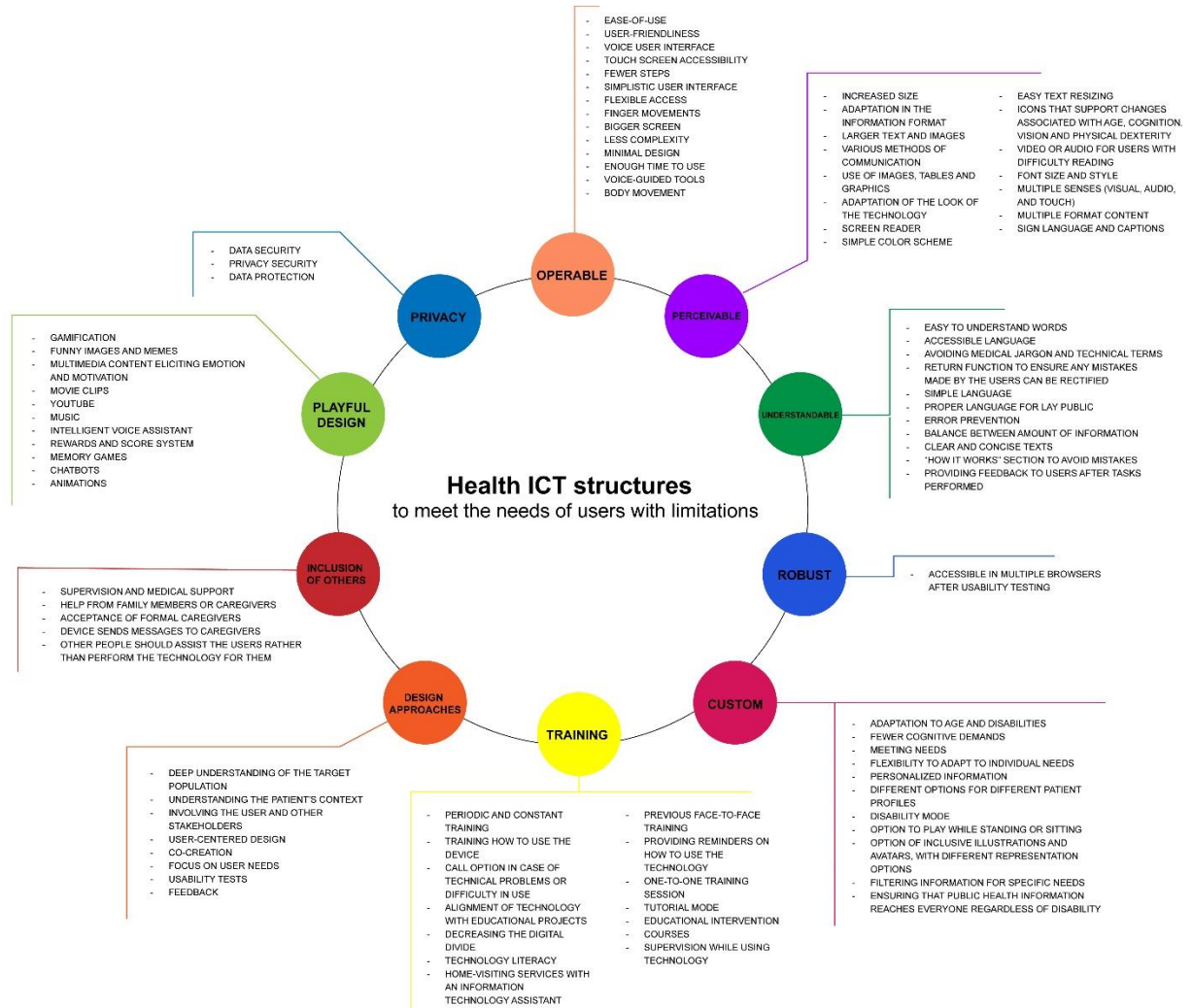
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## Appendix 1 - Model of ICT structures to meet the needs of users with limitations



### Operable user interface and navigation

Related to ease of use, it considers friendly devices that require fewer steps from the user and provide access flexibility. The option of using different information input modalities in the technology in addition to using the keyboard was evidenced, allowing users with different limitations to use ICTs, as in the case of voice-guided tools (BIEHL et al., 2021) or by movements of the body (BRANCO et al., 2021). Bigger screens (NAJM et al., 2020) and giving the necessary time for each user to be able to

use the device (TIERSEN et al., 2021) were also found in the studies as important health ICTs structures for users with limitations.

### **Perceivable information and user interface**

Concerns adapting the format of information for better use by more people. The possibility of presenting the content in different ways is the central point of this theme. This means that there are crucial many possibilities of use for users with limitations to be able to use health ICTs. The possibility of increasing font size and style (KAIRY et al., 2021), the availability of options for multiple senses (visual, audio, and touch) (GAGNON SHAIGETZ et al., 2021), and the presence of language of signs in videos and screen readers (DAI; HU, 2021) were some of the examples of easy adaptation of technologies for different user requirements. The changes required by each user vary according to the limitation, so adaptability must happen, allowing, for example, icons to be arranged in different shapes, sizes and colors, to meet different needs.

### **Understandable information and user interface**

Related to the ease of understanding of the information available in the technology, considering accessible language, clear and concise texts, and avoiding errors by the user. Avoid a lot of text (KAIRY et al., 2021), medical jargon and technical terms, return function (GIBSON et al., 2019), and provide feedback to users after performing a task to situate them on its correct use (TIERSEN et al., 2021), are some of the solutions that increase the user's understanding of information available in technologies. The study by Martin-Hammond, Vemireddy and Kartik Rao (2019) states that for elderly people with limitations, simple and direct language, considering a lay audience, is essential for their engagement with technology. Furthermore, the ICT should not ask many questions, with shorter content, in order to capture attention and be easy to understand for the target users.

### **Robust content and reliable interpretation**

Compatibility of the content with different tools and browsers is a structure related to robust content and reliable interpretation, having been observed in the study by Babatunde et al. (2020).

### **Custom technologies**

The possibility of adapting technology to specific needs is the central point of custom technologies. The articles emphasized the importance of knowing the user's needs, allowing representation in the technology, with options for their own avatar according to how the person sees themselves and the option to perform technology activities sitting or standing, for example (GAGNON SHAIGETZ et al., 2021), and an option of having a disability mode in technology, helping blind users and other groups in use (NIMMOLRAT et al., 2021).

### **Training**

User training for the use of technologies was evidenced as a way to reduce the digital divide (CONTRERAS-SOMOZA et al., 2020), by increasing technology literacy (CHRISTIANSEN et al., 2020). This training was brought by the studies from the perspective: of education to use, prior to the use of ICTs, through the alignment of technology with educational projects (CONTRERAS-SOMOZA et al., 2020), with periodic and constant training (RIKARD; BERKOWSKY; COTTEN, 2018), training on how to use the device (BARLOTT et al., 2019), home-visiting services with an information technology assistant (JAKOBSSON et al., 2020), educational intervention courses (BIEHL et al., 2021), prior one-to-one face-to-face training with constant reminders on how to use technology (RAI et al., 2021); of technical support during the use of ICTs, such as call options for questions during use (ISERNIA et al., 2019) and supervision during use (BIEHL et al., 2021); and of tutorials for use, with a tutorial mode in the technology helping to perform each required user task (GAGNON SHAIGETZ et al., 2021).

### **Use of design approaches**

In-depth understanding of the target population, its needs, and its involvement is fundamental for the design of technologies for users with limitations (GIUNTI, 2018). User-centered design (PARK et al., 2019), co-creation with the users (FERGUSON et al., 2021), usability testing and user feedback (Petrescu-Prahova et al., 2020) are important in this process. The study by Najm et al. (2020) highlights that, for health ICTs to be structured for users with limitations, it is necessary to involve patients in the development process. This way, their specific requirements will be taken into account, and technologies will be easy to use.

### **Inclusion of others in the technology implementation process**

Related to the need to have other people with the users with limitations for the implementation of the technology, since these people do not manage it in the place of the users, in order not to take away their independence (BARLOTT et al., 2019). The acceptance by formal caregivers of the implementation of technologies (CONTRERAS-SOMOZA et al., 2020), supervision and medical support (URBAN, 2017), and triggering device warnings to caregivers (ANISHA et al., 2020) are some of the structures considered important. The users' lack of digital skills means that families, caregivers and professionals need to play crucial roles in the management of technology, in order to assist in the process of use, as in the case of blood pressure technologies for stroke patients (RAI et al., 2021).

### **Playful design**

Users with limitations are more interested in using ICTs when ludic elements are associated, so that their use is facilitated. Inputting memory games in ICTs for patients with cognitive impairments, for example, proved to be an important resource for the user to be able to use ICTs, in addition to being a resource that assists in memory rehabilitation (MINEN et al., 2021). Funny images and memes (BARLOTT et al., 2021), Youtube, music (CHIU; WU, 2019), intelligent voice assistants for on-device health issues (MARTIN-HAMMOND; VEMIREDDY; KARTIK RAO, 2019), and reward to motivate use (GAGNON SHAIGETZ et al., 2021) were some of the structures

suggested in relation to playful design. It is especially related to users with cognitive impairments. The study by Minen et al., (2021) points out that ICTs should be used to help people with neuropsychiatric conditions to engage in meaningful and pleasurable activities, such as cognitive stimulation and physical activities, as well as technologies to enhance social participation, contact, and support.

### **Privacy guarantee**

Data protection and security (BIEHL et al., 2021) and privacy security (MARTIN-HAMMOND; VEMIREDDY; KARTIK RAO, 2019) were considered points of attention for the design of health ICTs for users with limitations. In the article by Urban (2017) the elderly were afraid that sensors could expose their daily activities, their sexual practices, and their lifestyles, and this could be embarrassing. The study by Kairy et al. (2021) found that despite the interest of individuals with physical disabilities with mobility limitations to be interested in socializing with people going through the same situation through ICTs, they would like to know what information was being shared, demonstrating concern with confidentiality.

**4 ARTIGO 2**

**Pontos críticos relativos a acessibilidade e inclusão em um serviço de oncologia: um estudo de caso para a proposição de TICs**

***Critical points concerning accessibility and inclusion in an oncology service: a case study for the proposition of ICTs***

## **Critical points concerning accessibility and inclusion in an oncology service: a case study for the proposition of ICTs**

**Abstract:** Health services have a number of barriers related to accessibility and inclusion, negatively affecting the experience in healthcare. So, this study aims to: (i) identify the critical points of the patient's journey regarding accessibility and inclusion in a Brazilian outpatient oncology service; (ii) understand the needs of people with disabilities and possible solutions for the health service according to their needs; and (iii) discuss the potential of ICTs to improve aspects of accessibility and expand inclusion in the service. A case study was carried out, with interviews and non-participant observations in an oncology service and a design workshop. Architectural, communicational, methodological, instrumental, programmatic and attitudinal barriers were observed in the service, and opportunities were identified for the implementation of technologies, mainly related to the difficulty of orientation and location in the service, signs with a lot of information, lack of accessible signs for multiple disabilities, large environment, verbal call, lack of comprehensive documentation, constant visits to the service, anxiety and pain about the disease and treatment, personal organization of documents and appointments, and lack of confidence and understanding about the treatment. Although many solutions are important and relevant to the context, the solution was mainly focused on a customized mobile health application for the service that brings advances to inclusive design by solving the critical points related to accessibility and inclusion in the service, allowing customization options for disabilities, giving patients choice, strengthening patients' autonomy, and allowing privacy. In addition, the implementation of ICTs as a solution to accessibility problems in the health service depends on the structuring of these technologies in relation to digital accessibility for users with limitations, as well as an inclusive culture in the service.

**Keywords:** Inclusive design; ICTs; accessibility; oncology; patient journey; health services

## 1 INTRODUCTION

A recent survey by the Brazilian Institute of Geography and Statistics (IBGE) found that 8.4% of the Brazilian population aged 2 years or more is disabled (IBGE, 2022). Despite a fairly representative number of people with disabilities (PwD) and Brazilian legislation guaranteeing the right to health for all - considering principles of accessibility and equity - there are many difficulties faced by these people in the context of health services (AMARAL et al., 2012). And this seems to be a global challenge, in which health services have a number of bottlenecks related to accessibility and inclusion, negatively affecting the experience in healthcare (BUCOLO; MATTHEWS, 2010; UNDESA, 2016; WHO, 2020a).

The focus of this study is on patients with cancer, because it is a chronic disease and, for this reason, it leads to a lot of complexity for health systems (PHILLIPS; CURROW, 2010). In addition, one of the points of interest focuses on the multiple vulnerabilities found in the oncological context. Cancer is a risk factor for the development of disabilities, both related to the physical functioning of the human body (HEWITT; ROWLAND; YANCIK, 2003), and to cognitive functioning (ACS, 2020). On top of that, people who already have some kind of previous disability or reduced mobility, can also develop cancer and, in this way, lose capabilities. So, cancer may arise in a context in which vulnerability is already present. Elderly people, for example, can be diagnosed with cancer and, at the same time, are more likely to experience other comorbidities, chronic diseases, delirium, dementia, and reduced mobility (CARRECA; BALDUCCI; ESTERMANN, 2005; ROH et al., 2014; ESTAPÉ, 2017). Likewise, people with prior disabilities to cancer may receive the diagnosis and start to face new barriers regarding accessibility in their daily lives (SAKELLARIOU et al., 2019).

Concerning adequate access for all people to health services, some principles need to be considered, especially accessibility, which is related to the needs of different population groups (LIU, 2018). Considering the multiple vulnerabilities evidenced in the context of cancer, there are a number of possible barriers faced by patients, since inadequate access to health services by PwD is understood as an accessibility barrier

to health services (WHO, 2022). In this study, we highlight the classification of barriers proposed by Sasaki (2009), which presents them as dimensions of accessibility: architectural, communicational, methodological, instrumental, programmatic, and attitudinal.

In view of the existing barriers, if accessibility to services is not adequately addressed, the obstacles will be so significant that they will make access to healthcare unfeasible for individuals with some type of limitation (CASTRO et al., 2010). This matters from the perspective of the patient experience, which is strongly impacted by aspects of the patient's journey through the health service, in which there are a series of points of contact, from admission to exit (GUALANDI et al., 2021). Understanding the patient's journey and each of their touchpoints is a valuable tool for designing services that optimize the experience and generate value, both for the patient and for the organization providing healthcare (SIMONSE; ALBAYRAK; STARRE, 2019).

Still in this context, information and communication technologies (ICTs) play an important role in defining health solutions, considering their potential to generate improvements in the quality of services provided, patient experience, provider and patient satisfaction, institutional outcomes, the health of the population as a whole (LI; CARAYON, 2021), and the reduction of inequalities in healthcare (UN, 2021). More than that, the International Telecommunication Union (ITU) also points out that ICTs have the potential to remove barriers related to accessibility and inclusion for vulnerable people, including their access to healthcare (ITU, 2013).

Therefore, we understand that inclusive design - a design philosophy that seeks to include as many people as possible in its solutions (GOODMAN-DEANE et al., 2014) - may contribute to enhancing PwD's journey through health services, improving their experience. The theoretical gap in this study is to relate inclusive design, accessibility and inclusion in healthcare contexts, and ICTs. That said, this study aims to: (i) identify the critical points of the patient's journey regarding accessibility and inclusion in a Brazilian outpatient oncology service; (ii) understand the needs of people with disabilities and possible solutions for the health service according to their needs; and (iii) discuss the potential of ICTs to improve aspects of accessibility and expand inclusion in the service.

## 2 BACKGROUND

This session will bring the background on which the discussion will be anchored, and is divided into the three main themes of this study: accessibility, inclusive design and patient journey in health services, and ICTs in healthcare.

### 2.1 ACCESSIBILITY

The concept of accessibility is addressed by the Brazilian Law for the Inclusion of Persons with Disabilities (No. 13,146), in its Article 3, Item I. The Brazilian Association of Technical Standards (ABNT) also provides the same definition of accessibility in Brazilian Standard 9050 (NBR 9050/2020). The concept places accessibility as a possibility and condition for the safe and autonomous use of spaces, furniture, urban equipment, buildings, transport, information and communication by PwD or reduced mobility (BRASIL, 2015; ABNT, 2020). In the digital context, accessibility means allowing everyone, including the PwD, full access to digital content (IPEDIS, 2023). Considering the health context, the concept is related to the possibility of access to health services (LIU, 2018).

In this scenario, it is important to understand the concepts about PwD and people with reduced mobility. Brazilian Decree No. 6949, of August 25, 2009 promulgates the International Convention on the Rights of Persons with Disabilities, and brings the definition that PwD are those who have long-term impairments of a physical, mental, intellectual or sensory nature, which in interaction with barriers, can obstruct their full participation and effective in society on equal terms with other people (BRASIL, 2009). Regarding people with reduced mobility, Brazilian Decree No. 5,296, of December 2, 2004, conceptualizes them as those who, not fitting the concept of PwD, have, for whatever reason, difficulty moving, permanently or temporarily, generating effective reduction of mobility, flexibility, motor coordination and perception (BRASIL, 2004).

These people face barriers in accessing health services, defined by Sasaki (2009) as architectural, communicational, methodological, instrumental,

programmatic, and attitudinal. The architectural dimension concerns the physical environments necessary for full and effective participation in society without infrastructure barriers (SASSAKI, 2009). The World Health Organization (WHO) points out that health infrastructure is generally insufficient for PwD (WHO, 2020b). Therefore, architectural issues are of special attention in NBR 9050 in relation to wide doors, spacious toilets, accessible faucets, good lighting, good ventilation, ergonomically accessible furniture, accessible routes, clear facilities and circulation, among others (ABNT, 2020). The study by Haron, Hamid and Talib (2010) points out that well-planned hospital layouts improve accessibility, experience and quality of the service provided.

Communication barriers concern problematic transmission of information to and between people (SASSAKI, 2009). WHO states that communication barriers are related to limited availability of written material or sign language interpreters at health services, inaccessible format of information (absence of Braille and large print, for example), and use of jargon that complicates the understanding of information (highlighting the lack of playful language, with visual materials for explanation as an example) (WHO, 2020b). NBR 9050 has regulations in this regard, related to signage, tactile floors, Braille, Brazilian sign language (Libras), etc. (ABNT, 2020). The study by Agaronnik et al. (2019a) portrays different forms of communication between doctor and patient depending on the type of disability the patient had - deaf or hard of hearing, blind or visually impaired, and with intellectual disability - demonstrating that effective communication is crucial for achieving patient-centered care.

Methodological accessibility concerns the absence of barriers in study methodologies and techniques, leisure, work and education, relating more to teaching processes in classrooms (SASSAKI, 2009). The instrumental aspect of accessibility concerns the absence of barriers in instruments, tools, utensils, caused by lack of adaptation (SASSAKI, 2009). In this context, WHO points out that assistive products are important in the context of health services, precisely because they are adapted to specific needs, allowing for an improvement in the participation of PwD (WHO, 2020b). NBR 9050 also provides guidelines in this regard, regulating the design of technologies and assistive products that can meet individual requirements. The study by Pharr

(2013) highlights the importance of accessible medical equipment so that patients with disabilities have their needs met. For example, the research by Agaronnik, El-Jawahri and Iezzoni (2021) describes necessary requirements for mammography devices to meet the particularities of women with physical disabilities, having to be accessible in a way that does not impose barriers to the performance of exams by these patients.

The programmatic dimension concerns the barriers (most often invisible) that may be embedded in public policies, legislation, norms, etc. (SASSAKI, 2009). The existence of laws, decrees, policies and regulations in Brazil that establish the rights of PwD, in addition to defining guidelines for accessibility in public environments, legitimizes the programmatic dimension. However, it is important for health services to have disability-inclusive internal policies that recognize the existence of these people in the service, planning how their care will be and the resources necessary to provide them with an accessible and quality service (WHO, 2020b). The study by Agaronnik et al. (2019b) verifies this issue in a practical way, when verifying that many doctors demonstrate superficial knowledge about their legal responsibilities with patients with disabilities.

Finally, attitudinal accessibility concerns the absence of prejudice, stereotypes, stigmas and discrimination in society's behaviors towards PwD (SASSAKI, 2009). Law 13,146, in its second chapter, deals with non-discrimination against PwD, emphasizing the equal treatment and opportunity of these people in society (BRASIL, 2015). WHO relates attitudinal barriers to lack of knowledge and professional training to deal with patients with disabilities (WHO, 2020b).

## 2.2 INCLUSIVE DESIGN AND PATIENT JOURNEY IN HEALTH SERVICES

Inclusive Design (ID) is a design philosophy that seeks to consider the needs of individuals during the design process of a product, considering those with reduced functional capability (PERSAD; LANGDON; CLARKSON, 2007). In recent years, ID concepts have gradually been used in services as well, in order to improve customer experience as well as the sustainability of business development (LIU, 2018). Seeking to expand the target public of products and services, ID takes into account the desires,

needs, expectations and experiences of all (BURGSTAHLER, 2001; PATTISON; STEDMON, 2006; GOODMAN-DEANE et al., 2014; GOMES; QUARESMA, 2018). For this, ID has some principles: putting people at the center of the design process; recognize diversity and difference; offer options when a single solution is not capable of covering all; provide flexibility of use; and designing solutions that are convenient and enjoyable for everyone, all of them making environments, products, and services easier to use (CABE, 2006). Waller et al. (2015) highlight that, for the implementation of ID strategies, it is crucial to understand the population diversity, as well as responses to this diversity, through informed design decisions. Thus, ID concepts need to have as a goal the ability to be accessible and attainable by “all people”, and must include all existing diversity (MEDEIROS; ACIOLY; SILVA, 2015).

Regarding the factors considered by ID, they focus on human abilities. Thus, when designing an inclusive service, different users must be recognized, considering that many of them may have their needs changed throughout their lives (GOMES; QUARESMA, 2018). In addition, all individuals, at some point, may experience some type of situation that is considered as a limitation, whether permanent (e.g. elderly people with memory loss); temporary (e.g. pregnant women may undergo certain restrictions and limitations during the time of pregnancy); or momentary (individuals without any apparent limitation may have difficulties depending on the context in which they are inserted) (GOMES; QUARESMA, 2018; WHO, 2022). However, although ID is a design philosophy that aims to include as many people as possible, not looking at just one disability, it is incorrect to imply that it is always possible to design considering the needs of the entire population (COLEMAN et al., 2007). ID is also about modularity that if combined expands the inclusion of people (IDRC, 2023).

Concerning ID in the context of health services, both the health needs of patients and the characteristics of the service should be taken into account (LIU, 2018). When talking about services, we need to understand it as a process, filled with steps and tasks, which the user goes through. In this scope, the user journey is framed, which consists of the process of experiencing the service through several touch points by means of the user's viewpoint (KANKAINEN et al., 2012). The user journey is extremely important from the perspective of service design, since it makes it possible

to visualize a large picture that contains the entire route taken by a user, the components of each process, and the experiences, making it possible to identify needs and provide improvements (KANKAINEN et al., 2012). In health services, the user journey is known as the patient journey, and represents "the time sequence of what happens to the patient, especially during transitions of care" (BELEFFI; MOSCONI; SHERIDAN, 2021, p. 119). Liu (2018) conceptualizes patient journey as the process they will go through to receive healthcare. Simonse, Albayrak and Starre (2019) point out the need to consider the point of view of different patients in the construction of the journey, in order to understand whether or not they experience similar situations in the service, bringing more robustness to the journey.

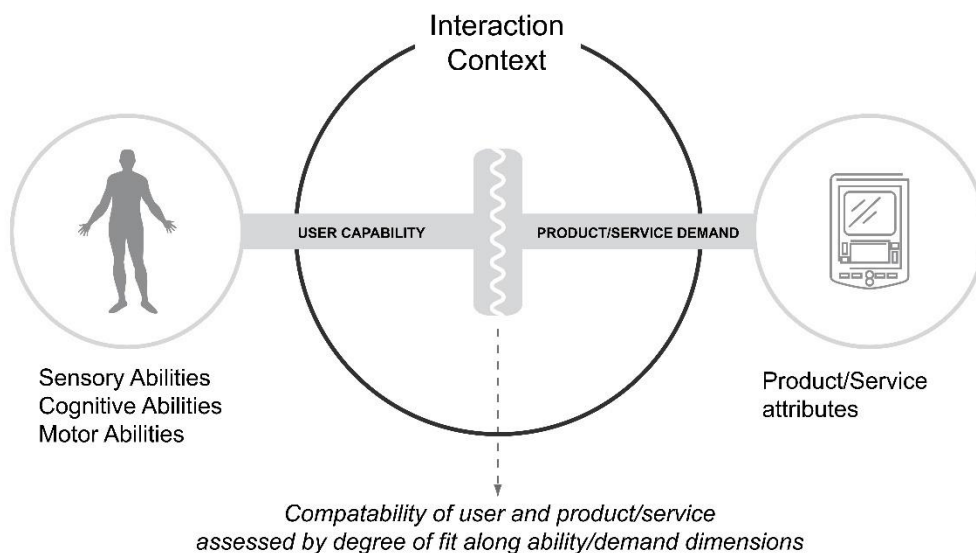
During this journey, there is an interaction between the demand of the services (attributes of the service and the health system) and the capabilities of patients (attributes of the users) in a context that is determined by the characteristics of who provides and who uses the service. Thus, if the health service has a greater demand than the capabilities of the patients who will use it, most likely these patients will not be able to access it, and may be excluded (PERSAD; LANGDON; CLARKSON, 2007; LIU, 2018).

It is in this context some capabilities arise to be taken into account for the inclusion or exclusion of individuals in the use of a product or service. These capabilities were based on a survey conducted in the United Kingdom between 1996 and 1997, called Disability Follow-up to the 1996/97 Family Resources Survey (GRUNDY et al., 1999), and were later defined in: vision, hearing, thinking, reach and dexterity, and mobility (CLARKSON et al., 2007). Vision concerns the perception of the world in images, movement and color, being necessary for the interaction with objects and environments. Hearing consists of the ability to interpret sound vibrations, allowing speech perception and, thus, constituting the basis of communication with other individuals. Thinking or cognition refers to how people respond to sensory perceptions of the world. Dexterity concerns the ability to grasp and hold objects and perform fine finger movements in handling small objects; while reach concerns the ability of one or both arms to reach in front, above the head or behind the back of the individual. Finally, mobility or locomotion is related to the ability to move and walk in environments, as

well as being able to maintain the body's balance to perform any activity that requires movement (CARDOSO et al., 2007).

These capabilities are particularly important, since the interaction with a product or service normally requires perception (sensory capability to perceive the environment or object), thought (needed to process the information received by the senses), and action (pressing a button or going to an environment to receive care, for example). It is crucial to consider motor, sensorial and cognitive capabilities together so that the cycle occurs in a complete way, where users can understand and go through all the processes. Once users experience loss of capability, access may be difficult (CLARKSON et al., 2007; LIU, 2018). From this perspective, the capability-demand theory arises (Figure 1), which, according to Persad, Langdon and Clarkson (2007), means that all products and services have a capability-demand from the user who will use them. In the case of healthcare, users need to have the necessary capabilities to access and use the service throughout their journey, performing tasks that require their capabilities. Thus, ID needs to ensure that service demand does not exceed user capabilities, so that there is no exclusion (LIU, 2018).

**Figure 1 - Capability-demand theory**



Adapted from Persad, Langdon and Clarkson (2007)

Thus, it is evident that ID has the potential to improve the user experience, considering population diversity (GOODMAN-DEANE et al., 2018). ID can contribute to the redesign of health services with regard to accessibility and inclusion, in order to consider and make its use possible and, consequently, make the experience positive for all users, considering those who face limitations caused by environments in which they seek to insert themselves (BENIUK; WARD; CLARKSON, 2011; LIU, 2018).

### 2.3 ICTs IN HEALTHCARE

With the advent of Industry 4.0 (I4.0), also known as the Fourth Industrial Revolution, a series of information and communication technologies (ICTs) were developed and implemented in order to bring improvements to the industry and its production methods - being known as a revolution of digital platforms (LASI et al., 2014; XU; XU; LI, 2018; WEHDE, 2019). I4.0 makes use of the combination of artificial intelligence, smart sensors and data analysis to optimize manufacturing (XU; XU; LI, 2018).

In view of the proposed innovations and the ability to bring changes and solutions to the context, ICTs has been identified as a way to improve processes in health services, in addition to improving the user experience and accessibility (MASTRONARDO et al., 2021; HALEEM et al., 2022). Mainly, with the emergence of the COVID-19 pandemic, ICT have gained strength in the health area worldwide, supporting the delivery of health virtually and helping to face complex challenges that have arisen due to social distancing (MBUNGE et al., 2022). Considering the protagonism of ICTs in health institutions in recent years, and the emergence of Health 4.0, it is important that the concept of ICTs in health, its benefits of use and related solutions are explained. Health ICTs encompass all digital technologies that facilitate the electronic capture, processing, storage and exchange of information (GAGNON et al., 2012, p. 241). They refer to the application of ICTs in the health context, considering the promotion of remote care, clinical support, and knowledge transfer (GAGNON et al., 2013).

The potential of ICTs to bring solutions to the complex health environment is of particular interest to this study. It is crucial that emerging technologies be identified, as well as their possible applications in solving problems in health services, especially regarding aspects of accessibility. Some technologies are identified in the literature, which are in constant growth and application in the health area, bringing various contributions. We highlight in this analysis: Internet of Things (IoT) (AL-JAROODI; MOHAMED; ABUKHOUSA, 2020; TORTORELLA et al., 2021; ALI; ALAHMAD; KAHTAN, 2023; HALEEM et al., 2022), Telemedicine/Telehealth (HALEEM et al., 2022; MBUNGE, 2022), Big Data (AL-JAROODI; MOHAMED; ABUKHOUSA, 2020; HALEEM et al., 2022), Artificial Intelligence (TORTORELLA et al., 2021; ALI; ALAHMAD; KAHTAN, 2023; HALEEM et al., 2022; MBUNGE, 2022), Virtual Reality (TORTORELLA et al., 2021; HALEEM et al., 2022), Mobile Health Applications (TORTORELLA et al., 2021; HALEEM et al., 2022; MBUNGE, 2022), among other digital health technologies. Table 1 shows the applicability of these ICTs in the context of health services, according to the literature.

**Table 1 - Applicability of ICTs in healthcare**

ICTs	Concept in healthcare	General and specific applications in the health context	References
Internet of Things (IoT)	Collection, monitoring, and control of healthcare data by the means of a digitally connected network of intelligent sensing devices and physical objects (BELFIORE; CUCCURULLO; ARIA, 2022).	Healthcare Monitoring System	WAN et al., 2018; SWAROOP et al., 2019; MANI; SINGH; NIMMAGADA, 2020; PEREZ et al., 2023
		Remote monitoring of vital signs and automated delivery of medications	SWAROOP et al., 2019; ANGERMANN et al., 2020
		Sensors implemented in wheelchairs for better driving and emergency control	YANG et al., 2017; UPENDER; VARDHINI, 2021; PEREZ et al., 2023
		Wearable devices	WAN et al., 2018; PEREZ et al., 2023
		Smart infrastructures (internet-connected toys and robotic systems deployed at home or health institution)	PEREZ et al., 2023
Telemedicine/ Telehealth	Telehealth is the use of technology for delivering health information, embracing a variety of tools to deliver virtual health services. Telemedicine is the remote	Video consultation	RALLIS; ALLEN-TEJERINA, 2020; ARIGHI et al., 2021; CARUSO; LIN; MALKOWICZ, 2022

	delivery of healthcare, such as health appointments, diagnoses, prescriptions, and treatment plans digitally (CUSHING, 2022).	Chatbots	NADARZYNSKI et al., 2020; SEITZ; BEKMEIER-FEUERHAHN; GOHIL, 2022
		Live web chats	RALLIS; ALLEN-TEJERINA, 2020; NADARZYNSKI et al., 2020
		Online information exchange between specialists about patient cases (Tele-expertise)	KAMSU-FOGUEM et al., 2015; HALLEM et al. (2021)
		Telemonitoring through electronic equipment	KAMSU-FOGUEM et al., 2015; HALEEM et al., 2021
Big Data	With the digitization of the large volume of patient data generated in the health sector, Big Data is a technology that takes care of this data set in real time, helping to make valuable decisions based on data patterns, with the aid of machine learning algorithms (KUMAR et al., 2020).	Electronic health records	ZEADALLY et al., 2019; LV; QIAO, 2020
		Real-time monitoring	KALID et al., 2017; ZEADALLY et al., 2019
		Predictive analytics	JANKE et al., 2016
		Preventive healthcare	RAZZAK; IMRAN; XU, 2019
Artificial Intelligence (AI)	Artificial intelligence seeks to build computer systems that can represent or replicate the human thought process (AMER, 2021; JIMMA, 2023), providing improvements in healthcare from diagnostics to treatment (BOHR; MEMARZADEH, 2020).	AI-assisted robotic surgery	YU; BEAM; KOHANE, 2018; DAVENPORT; KALAKOTA, 2019; JIMMA, 2023
		Virtual nursing assistants	JIMMA, 2023
		Aid clinical judgment or diagnosis	YU; BEAM; KOHANE, 2018; DAVENPORT; KALAKOTA, 2019; JIMMA, 2023
		Image analysis	YU; BEAM; KOHANE, 2018; JIMMA, 2023
		Workflow, and administrative tasks	DAVENPORT; KALAKOTA, 2019; JIMMA, 2023
		Chatbots	NADARZYNSKI et al., 2019; XU et al., 2021
Virtual Reality	Allows computer-based models of the real world to be generated, promoting human interaction with these models through human-computer interfaces (LÁNYI, 2006), that provide sensations (visual, haptic, auditory, etc.), which gives the user a sensation of presence in the virtual world (SETH; VANCE; OLIVER, 2010). In healthcare, virtual	Rehabilitation	ISERNIA et al., 2019; SINGH et al., 2020; KOHLI et al., 2022
		Reduction of pain and anxiety	WIEDERHOLD; MILLER; WIEDERHOLD, 2018; HOFFMAN et al., 2019; SINGH et al., 2020; JANSSEN et al., 2022

	reality usually has acoustic and visual resources, or multiple projection environments, so that it is possible to learn and deal with problems/cases in real time in a more productive way (SINGH et al., 2020).	Digital wayfinding projects	LEE, 2010; DEVLIN, 2014; AL-SHARAA et al., 2022
		Patient education	SINGH et al., 2020; van Der KRUK et al., 2022
Mobile Health Applications	Health apps are application software programs providing mobile solutions for healthcare and prevention, which can be downloaded on smartphones, tablets, and other mobile communication devices (ZHANG; KOCH, 2015).	Patient/clinical monitoring	VENTOLA, 2014; NARANJO-ROJAS; PERULA-DE-TORRES; MOLINA-RECIO, 2019
		Rehabilitation	NUSSBAUM et al., 2019; RAMEY et al., 2019
		Patient education	BOHN et al., 2017; NUSSBAUM et al., 2019
		Digital wayfinding projects	HARPER et al., 2020; MACKETT, 2021
		Information management (patient's medical record and history)	MAHMUD; SORONI; KHAN, 2021
		Communication and consulting (telemedicine)	VENTOLA, 2014; TAHA et al., 2022
		Pain management	THURNHEER et al., 2018; RAMEY et al., 2019
		Health management	MANO, 2021
Other digital health technologies	-	Wayfinding touchscreen interfaces (kiosks)	WRIGHT et al., 2010; HARPER et al., 2020
		Social media for patient communication and support	KUWABARA; SU; KRAUSS, 2019

Elaborated by the authors (2023)

With specific regard to accessibility, Mastronardo et al. (2021) points out that ICTs are timely for accessibility in health services. The International Telecommunication Union (ITU) determines which technologies facilitate accessibility in healthcare, highlighting the internet, software and applications, services and mobile devices, interactive devices, and emerging ICTs - which include, among other technologies, intelligent systems (ITU, 2013). There is, then, an opportunity to use ICTs in the context of accessibility and inclusion in health services. The systematic review by König-Klever et al. (2023) (ARTICLE 1) also addresses ICTs with great potential for the context of accessibility: digital health - with wearable devices and apps -, use of the internet, mobile devices, television, virtual reality, assistive technologies, telemedicine, ICTs in general, among others more specific. These findings show the

potential of ICTs that have been present in society for some time as well as current technologies to collaborate with accessible projects that promote inclusion in health.

Although there are studies that show some relationship between the implementation of ICTs and accessibility improvements in health services, few studies explore this aspect in-depth in the literature. Studies of accessibility technologies that impact health services are generally related to physical signaling processes. We highlight the study by Wright et al. (2010) who propose using audio to support animated route information in a hospital, and the study of Salawu (2022) which proposes an inclusive wayfinding project so that PwD could have access to hospital signage information (such as tactile maps). Despite being studies that bring improvements in accessibility aspects in services and include patients with disabilities, to the best of our knowledge there are no studies that explore technologies more comprehensively as a way to improve critical accessibility points throughout the journey of a patient by health services.

### **3 METHOD**

This research is a case study and was carried out in two stages. Firstly, in order to map the journey of oncological patients in the service and understand the critical points regarding accessibility and inclusion, non-participant observations and interviews with patients, caregivers, and service professionals were carried out in a private outpatient oncological service of a Brazilian hospital. After the first stage was performed, with data compiled on the critical points and barriers related to accessibility and inclusion in the analyzed service, a workshop was held with cancer patients, health professionals, PwD, and specialists in the areas of design and disabilities, in order to raise possible solutions. All stages of the research were performed by two researchers.

Concerning research ethics, the study was approved by the UFCSPA's Institutional Review Board (CAAE 55467222.5.0000.5345). The hospital also provided a term of acceptance to carry out the research. The study has complied with the Data Protection Act, which requires personal, professional, and institutional data to be

anonymized. In the sections below, we present the case and detail the data collection procedures.

### 3.1 CASE PRESENTATION

The case to be studied consists of a private outpatient oncological service of a Brazilian hospital that assists 86 cancer patients, which is located in a clinical center that includes a series of clinics, from laboratory tests to imaging tests, and several medical specialties, including the analyzed oncology outpatient service. The service assists patients from health insurance and patients who pay privately. The only procedure performed at the service is chemotherapy. Therefore, cases of surgery, radiotherapy, and other oncological treatments are referred to other services. Five oncologists, four oncology nurses, a receptionist and two administrative assistants are part of the team. Pharmacists, despite taking the requested medication to the service, work in an oncology pharmacy located in another building close to the service.

The service consists of a reception, an administrative room, a pantry room, a file room, two doctors' offices, and the chemotherapy area, which is made up of five chemotherapy rooms, a nursing area, and two bathrooms. The entrance doors of the institution where the service is placed are in the parking lot (which has 2 floors) and in the main entrance door that is directly on an urban sidewalk. The service is located on the first basement floor of the institution, and patients can use both stairs and elevators to reach it. The institution is located next to a hospital, which also has an oncology service. Figure 2 brings a compilation of images of the institution and the service.

### 3.2 INTERVIEWS AND NON-PARTICIPANT OBSERVATIONS

Observations took place over 15 days, in shifts and times suggested by the service during June and July of 2022, totaling approximately 24 hours of observation. The researchers kept a field diary in which they wrote down their observations of what had happened, the doubts that arose (to be asked later to the service professionals), and the critical points observed related to the patients' accessibility to the service.

**Figure 2 - Institution and service images**



Elaborated by the authors (2023)

Regarding the interviews, 13 patients, 5 caregivers, and 4 service professionals were interviewed from June to September of 2022. Patients were selected by convenience, according to availability and interest in participating in the interview. For this, nurses asked the patients undergoing chemotherapy who would like to be interviewed by researchers. Those who accepted were selected. With regard to companions and service professionals, those who indicated an interest in participating were also selected. Patients were interviewed during the chemotherapy session, companions were interviewed during the patient chemotherapy session in the same room or in a separated one, and service professionals were interviewed at a convenient time, when the service was not in attendance.

The interviews followed a semi-structured script of questions, which varied according to the interviewee's profile: patient, caregiver, or service professional. For patients, the questions sought to understand the context of life, how the cancer diagnosis was reached, how the person dealt with the disease and the treatment, what were the side effects of the treatment, what limitations, comorbidities and disabilities they faced before and after the disease, what are the major post-cancer changes, how the person arrives at the service, what barriers are encountered, what are the suggestions for improving the service, knowledge about technologies, potential of technologies to improve service processes, etc. For caregivers, the questions were very similar, but seeking to understand their perspective on that patient who they accompany and care for. Regarding the professionals, the questions were aimed at understanding the user's journey through the service, processes, points of contact, perceptions, etc. During the observations and interviews, the researchers were attentive to the opportunity to implement technologies in the service that could improve the experience of patients in the service regarding accessibility and inclusion.

For data analysis, thematic analysis was performed (BRAUN; CLARKE, 2006). Through the transcriptions of the recordings of interviews and the field diaries of observations, relevant themes for the analysis were highlighted, generated through a deductive approach, based on the accessibility barriers pointed out by Sasaki (2009): architectural, communicational, methodological, instrumental, programmatic, and attitudinal. The themes were later discussed in relation to their potential for application of ICTs. Data was organized in a table divided into collected data, analytical categories, sources of evidence, and opportunity for technology implementation. To ensure the anonymity of respondents, patients will be identified as P1, P2, P3, P4, P5, P6, P7, P8, P9, P10, P11, P12, and P13; caregivers as C1, C2, C3, C4, and C5; and service professionals as SP1, SP2, SP3, and SP4. Information about the study participants is detailed in Table 2.

From interviews and observations, a user journey map was constructed based on Liu's (2018) model. Journey maps tell the story of the user's experience within a specific journey (STICKDORN; SCHNEIDER, 2011; LIU, 2018). Key interactions (activities and tasks), possible barriers and difficulties encountered (LIU, 2018),

behaviors, feelings, motivations and attitudes of the patient at each moment of the journey are identified (MCCARTHY, 2016). Our journey map helps to visualize the patient journey, user capability-related tasks, critical points related to accessibility and inclusion, and opportunities for ICT implementation.

**Table 2 - Information about the study participants**

Patients			
Participants	Age	Type of cancer	Capability losses (vision/ hearing/ thinking/ reach and dexterity/ mobility)
P1	75	Pelvic cancer	Thinking - confusion and forgetfulness aggravated by age and illness Mobility - several previous cancer surgeries and uses a walker
P2	62	Carotid cancer and liver metastasis	Vision - had paralysis many years ago, unrelated to cancer, and has compromised facial nerves Mobility - treatment-related fatigue
P3	59	Lung cancer and central nervous system metastasis	Vision - vision loss in the right eye due to radiotherapy Hearing - hearing loss in left ear due to radiotherapy Thinking - cancer has already touched on motor coordination Reach and dexterity - drops objects when feeling tingling Mobility - treatment-related fatigue
P4	67	Bowel cancer	Vision - vision loss with age Hearing - hearing loss with age Thinking - forgetfulness potentiated by anxiety and effects of treatment and age Reach and dexterity - trembles a lot as a result of the treatment Mobility - uses an ostomy bag and a colostomy bag and is unable to stand up for a long time, nor carry out his routine tasks
P5	72	Lymphoma	Vision - has cataracts and needs glasses all the time Thinking - memory loss prior to cancer Mobility - had two strokes in the past and became physically disabled; needs help with all daily tasks
P6	83	Pancreatic cancer	Thinking - forgetfulness aggravated by age and treatment Mobility - very weakened by treatment
P7	63	Ovarian, fallopian tube, and peritoneal cancer	Thinking - forgetfulness and memory loss aggravated by age and treatment
P8	80	Lymphoma	Hearing - hearing loss with age

			Mobility - back problem prior to cancer; loss of lean mass and stability in the legs due to treatment
P9	76	Endometrial cancer	Mobility - leg wear prior to cancer
P10	69	Lung cancer	Hearing - hearing with age Mobility - spine surgeries prior to cancer; some toes amputated due to diabetes; treatment-related fatigue
P11	53	Bowel cancer	None, despite having to use a colostomy bag
P12	32	Breast cancer	None
P13	67	Skin cancer	Vision - vision loss with age Hearing - hearing loss with age Thinking - forgetfulness and memory loss aggravated by age and treatment
<b>Caregivers</b>			
<b>Participants</b>		<b>Relationship with patients</b>	
C1		Family member of P3	
C2		Family member to P4	
C3		Friend of P6	
C4		Family member of P10	
C5		Family member of P12	
<b>Service professionals</b>			
<b>Participants</b>		<b>Profession</b>	
SP1		Oncological nurse	
SP2		Oncological nurse	
SP3		Oncological nurse	
SP4		Medical oncologist	

Elaborated by the authors (2023)

### 3.3 WORKSHOP

After collecting and analyzing data from interviews and observations, a workshop was also held as a design tool that generates ideas, concepts, and solutions to identified and presented problems (LIMA et al., 2016). The workshop took place in March 2023, in a single 3-hour meeting at a university building, was conducted by two researchers, and brought together 10 cancer patients (in treatment or survivors), two

caregivers, five professionals from oncology services, seven PwD (two blind, three deaf, and one person with a physical disability), and two specialists in the field of design and disabilities (one of them was also a sign language interpreter). Invitations to participate in the workshop were sent to the oncology service staff and posted by them on the social networks, reinforcing the presence of patients, caregivers, and professionals from the analyzed service or other services, and PwD. The specialists were contacted via the researchers' professional networks.

In order to bring different contributions to the journey of users in the oncology service, several people were involved in the workshop. The involvement of users in the workshop is important from the design perspective (PAGNAN et al., 2019), and with regard to ID, it is important that a diversity of users be involved in the development of solutions (FUGLERUD; HALBACH; SNAPRUD, 2021). For this reason, users with disabilities, even without being cancer patients, were invited to participate in the workshop. We understood that the perspective of these people was important for the construction of inclusive solutions to the analyzed service. So, the co-creation took place based on the themes of barriers to inclusion and accessibility, patients' experience during the health journey, and opportunities for ICTs implementation. The participants learned and performed creative and innovative problem-solving related to the specific issue (ØRNGREEN; LEVINSEN, 2017).

The workshop followed the design thinking method based on the four steps suggested by Kelley and Kelley (2013): 1. Inspiration; 2. Synthesis; 3. Ideation and experimentation; and 4. Implementation. Data was collected through photographs, observations, field notes, and recordings. First, the two researchers raised awareness about the subject, then the participants were separated into four groups, and at the end a debate was held between all the groups, raising points of interest. Participants were encouraged to write on sticky notes and use creativity to perform activities (TONETTO et al., 2021). Table 3 details the workshop schedule and Figure 3 brings a compilation of photographic records of the workshop.

Recordings of the workshop were transcribed and used in combination with the notes taken by the researchers, and the sticky notes used by the participants. Data was analyzed using thematic analysis (BRAUN; CLARKE, 2006). Two themes

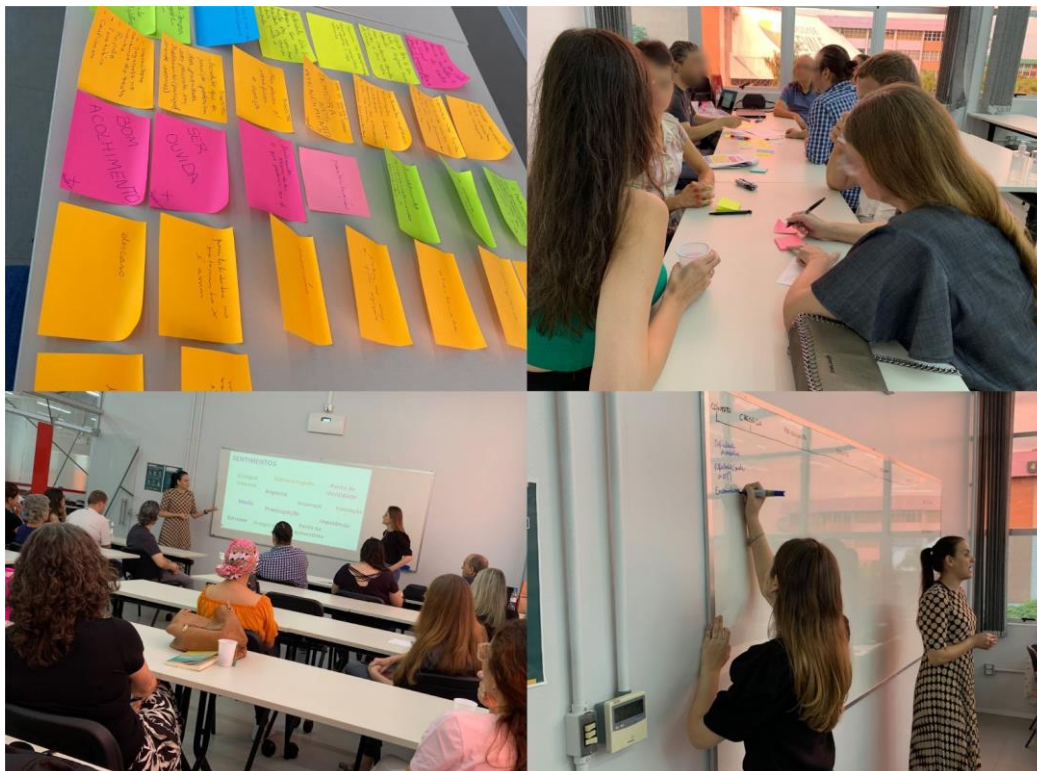
emerged from the collected data: solutions for health services; and solutions beyond the services.

**Table 3 – Workshop schedule**

Stages	Activities
Inspiration	<p>Presentation of research findings, with identification of accessibility barriers observed in the service, opportunities for implementing technologies, and explanation of the different groups present at the workshop.</p> <p>Presentation of users' journey through a health service through slides and speech.</p> <p>Presentation of design theories that guide the work.</p> <p>Definition of the problem to be worked on, using the brainstorming technique (THORING; MÜLLER, 2020).</p> <p>Generation of insights through the issues presented.</p>
Synthesis	<p>Division of participants into four groups.</p> <p>Initial exchanges of ideas on the issues addressed.</p> <p>Identification of common issues.</p> <p>Moment of exchanging experiences and defining the course of conversations in each group.</p> <p>Researchers went through the groups and generated insights, with more individualized problems for each group.</p>
Ideation and experimentation Implementation	<p>The groups received sticky notes, colorful pens, and papers with the drawings of the user journeys mapped by the researchers and schematics from the literature on ICT for users with limitations.</p> <p>Participants outlined solutions to the highlighted problems, based on their previous experiences.</p> <p>Participants wrote on sticky notes all the solutions they thought of and different implementation scenarios.</p> <p>After that, the groups had the opportunity to present their ideas to the large group.</p> <p>The ideas were written down by the researchers on a blackboard, in order to form a large compilation of ideas and solutions.</p>

Elaborated by the authors (2023)

**Figure 3 - Photographic records of the workshop**



Elaborated by the authors (2023)

## **4 RESULTS**

The results will be presented according to the two data collection instances: (i) interviews and non-participant observations; and (ii) workshop.

### **4.1 INTERVIEWS AND NON-PARTICIPANT OBSERVATIONS**

For data analysis at this stage, the themes of analysis were defined a priori based on the six aspects of accessibility by Sasaki (2009): architectural, communicational, methodological, instrumental, programmatic, and attitudinal.

#### **4.1.1 Architectural accessibility**

Through the observations, some findings were made in terms of the built environment of the service. We identified some architectural barriers in the

observations and in seven interviews. The construction of the building does not comply with a few established standards for accessibility. For example, there is no tactile and visual signage on the floor, seats for obese people, and accessible routes. Many interviewees complained about the trouble to get to the service, emphasizing that they always get lost and have a hard time finding the entrance. P12 and her caregiver, even without any disability, complained about always getting lost, even after having gone to the service more than once. They showed concern and empathy for patients with disability, highlighting:

*P12: Oh, no, even now we still get lost [...] we ran a lot, it went everywhere [...] we really get lost.*

*C5: Imagine a visually impaired person, they can't... Even on the floor there should be that thing for blind people.*

Even for people without any apparent disability, the institution's architectural space was confusing. This leads us to believe that the more vulnerable people are, the more difficult this process can be. For P7 this route seems to be more complex, because she always gets lost and finds it very difficult to get to the service, as reported:

*P7: ...the only thing is access to get to this place here. I get lost every time I come [...] I came through the garage, got lost, went up, down...*

These reports relate to issues of signalling in architecture. However, another topic emerged related to architectural accessibility, especially for PwD related to physical mobility. During the observations, we noticed that P5, when called by the doctor, staggered and held onto the walls until the doctor's office. This patient had no crutches or canes and, when interviewed, said that it was the same at home. Although this patient has a denial process, the service does not have crutches or handrails on the walls (only in the bathroom). So, even though he did not admit that the way he was moving around the service was not ideal, the observations showed the opposite.

Regarding technologies related to the architectural aspects of the institution and the service, almost none were observed. The only technologies available were the patient scheduling systems used by the nurses and secretary, the physicians' medical

record portal (which is not always used), and the television available in each individual chemotherapy room. Televisions are not smart and do not have an internet connection, so the patient only has the option of watching open television channels.

#### **4.1.2 Communication accessibility**

Considering that the built environment in which the analyzed service is located is large, with a lot of information and medical services around, and next to a hospital that provides the same type of services, communication barriers were found that are closely related to the architectural ones, mainly in terms of signage (since signs indicate information and communicate something). The absence of a tactile floor, for example, as much as is an architectural barrier, constitutes a communication barrier for those with total or partial vision loss, because the tactile floor transmits information to people who cannot see, guiding them in the environment.

Along the same lines, we observed that neither the institution nor the service has a Brazilian sign language (Libras) interpreter available who can meet the communication demands of deaf people. We also did not identify any type of staff to help people locate themselves in the service. Only a few security guards are in the institution, but without any training to deal with the various needs that may exist. Through the observations, we noticed that there are leaflets with the map of the institution in the parking lots, as well as some information signs, which indicate where the service is located. However, in addition to these features not being inclusive (e.g. they are not available in Braille and audible location devices), they are only available next to the car park elevators, and the signposts are in small print, in the middle of an amount of information about other services. In addition, the indicative signs were not designed considering legibility or clarity of information, and PwD sitting, standing or walking. A visual contrast that could facilitate reading by people with visual loss or cognitive decline was also not observed. Tactile symbols were also not identified anywhere. P7 pointed out that a larger sign indicating where the service is located would be helpful, and that in the elevators and other places in the institution this could

be better signaled. The three nurses interviewed also mentioned that communication could be improved throughout the entire institution, so that patients are less lost.

Another point related to communication accessibility that occurs when the patient is already in the service is that medical calls are verbal at the reception. Therefore, the patient needs to hear the call and go to the doctor's office. There is no call screen or other way to call the patient at that time.

Regarding communication between patients and service professionals, some barriers were also perceived. First, in all the interviews, whether with the nurses, the doctor, the patients or caregivers, we noticed that the moment before starting the treatment is the most difficult for all patients. This happens because sometimes it takes patients very long to receive a diagnosis, so when they receive it, they wish to start treating it as soon as possible. Furthermore, many receive the diagnosis as a death sentence, due to the stereotype that has been enacted about cancer in society. At that moment, patients feel powerless, fragile, and not knowing where to start. Although the service has a nursing consultation prior to the start of chemotherapy, many report that they do not understand much about what they are going through and the complexity of their diagnosis, which causes a lot of anxiety. P6 emphasized that she feels anxious about the treatment even after having already started it:

*P6: About the health area, we don't understand much [...] This delay of not knowing what the next step is [...] What is the way I'm going? It makes me so insecure.*

In the interview with P3, who is undergoing palliative treatment for a very advanced cancer, one more communication barrier was observed, related to trust. He reported that he does not feel completely safe with the treatment he receives, because he cannot be sure if this is the best treatment, considering the existence of many opinions and options. The patient, on the date of the interview, already had many cognitive impairments resulting from the metastasis. He highlighted several times that he was not sure, demonstrating distrust. C1 was also not completely satisfied and confident.

Still related to trust, during the interview with P1, we observed a situation that left the patient very insecure. Upon receiving another chemotherapy bag in the session, the nurse told the patient that it was the last one of the day, and that later she would be free to leave. However, P1 said that in previous sessions she had received, instead of three, four bags of chemotherapy. The nurses disagreed, and to prove it, they opened her medical record and said that the treatment was like that from the beginning. The patient did not agree and called a family member, reporting the situation and stating that she was sure that at other times she had received an extra bag in the session. P1 left the service that day full of uncertainty and insecurity. Despite having already been performing the chemotherapy protocol for some time in the same way, this patient was confused.

In fact, patients handle a lot of information, and, despite having a folder with past exams, P12 indicated that it would be interesting to have a booklet to better track information about the treatment and have everything more organized. She even found the idea of a digital booklet interesting.

In terms of communication, the only technologies used are WhatsApp, the clinic's social networks and a phone call in the post-chemotherapy week. In addition, the service leaves a 24-hour telephone available in case patients have symptoms or questions. Patients demonstrated to like this option, feeling safer with this availability of care at any time.

#### **4.1.3 Methodological accessibility**

Regarding the methodological aspects, through the observations we noticed that there are no adapted forms of care for PwD in the service. Regarding anamneses or patient filling forms, there are no adaptations designed for the diversity of needs.

Thinking about the autonomy of patients to answer questions, they always depend on someone at the service to fill in personal data. Blind, deaf and more severely cognitively impaired patients may not adapt to the conventional way of service processes, and we did not identify, through observations, adjustments in the way of obtaining information from users other than verbally.

#### **4.1.4 Instrumental accessibility**

The barriers of the instrumental category were evidenced in the observations, which showed the absence of some elements in the service. We found that the service does not explore the use of many innovative technologies (with the exception of cold caps and scalp cooling systems to prevent hair loss in some types of chemotherapy). But, more than that, we observe the lack of assistive technologies and devices. No adaptation is thought of in terms of products to meet PwD. Chemotherapy armchairs are not adaptable, televisions do not have inclusive adaptations (they are quite outdated), there are no call screens accessible at reception, among many other situations in which assistive products and technologies could be implemented to better meet all conditions.

We emphasize that only two patients were favorable of a possible insertion of technologies in the service, even though they had nothing negative to point out in relation to how processes are carried out today. The other patients showed disinterest when asked about technologies in the service and opportunities for improvement, either because of the difficulty in handling them or because they did not see how ICTs could bring improvements.

#### **4.1.5 Programmatic accessibility**

Barriers concerning programmatic accessibility were verified by some speeches and perception of lack of inclusive processes in the service. HP4, when questioned about the existence of PwD in the oncology service, reported that there are no blind and deaf patients who have already sought the service or that she has already seen in all her years of experience in oncology. However, PwD can also develop cancer, just like any other disease. P1, P2, P5 and P10, for example, have already arrived at the service with disabilities prior to cancer. However, we noticed that the service does not see them as PwD, because they have disabilities that are not obvious (such as blindness, for example). In addition, the fact that paraplegic, blind, deaf and autistic people, people with prostheses, among many other groups of disabilities, are not in

the service may concern much deeper issues, raising the question of why they are not there.

In addition, considering that patients without disabilities can develop them due to cancer and treatment, the discourse of the non-existence of PwD shows that there are no disability-inclusive internal policies to serve these people, who have particularities and specific needs. There are no protocols for PwD healthcare, because their presence in the service is unknown. As a result, we observed that there are no inclusive projects in the institution or in the service. In interviews with health professionals, we noticed that they understand accessibility only as adapting door sizes for wheelchairs, or accessible bathrooms, but the scope is much broader and does not concern only physical aspects.

We also identified another barrier related to programmatic accessibility. P12 and C5 complained about having to do the blood test the day before the consultation, because the trip is far away for them to go two consecutive days, making it tiring, especially for patients undergoing chemotherapy. If patients do not have good test results, and the doctor understands that they are vulnerable to undergo chemotherapy that day, they will be sent away with a return appointment scheduled for another day. In view of this, there is no guarantee that the patient will undergo the chemotherapy session on the day that the exams are taken to the doctor. And this can generate more than two days of travel (one to carry out the exam in a laboratory, one to take the exams to the doctor and undergo the chemotherapy session, and one to return if it has not been possible to carry out chemotherapy the previous time due to a fragile condition). This is also related to internal policies, and that due to excessive displacement, can cause excessive effort for PwD.

#### **4.1.6 Attitudinal accessibility**

Regarding aspects of attitudinal accessibility, barriers were evidenced related to lack of professional training to deal with patients with disabilities, associated to the absence of standardized processes and internal policies aimed at them. We did not

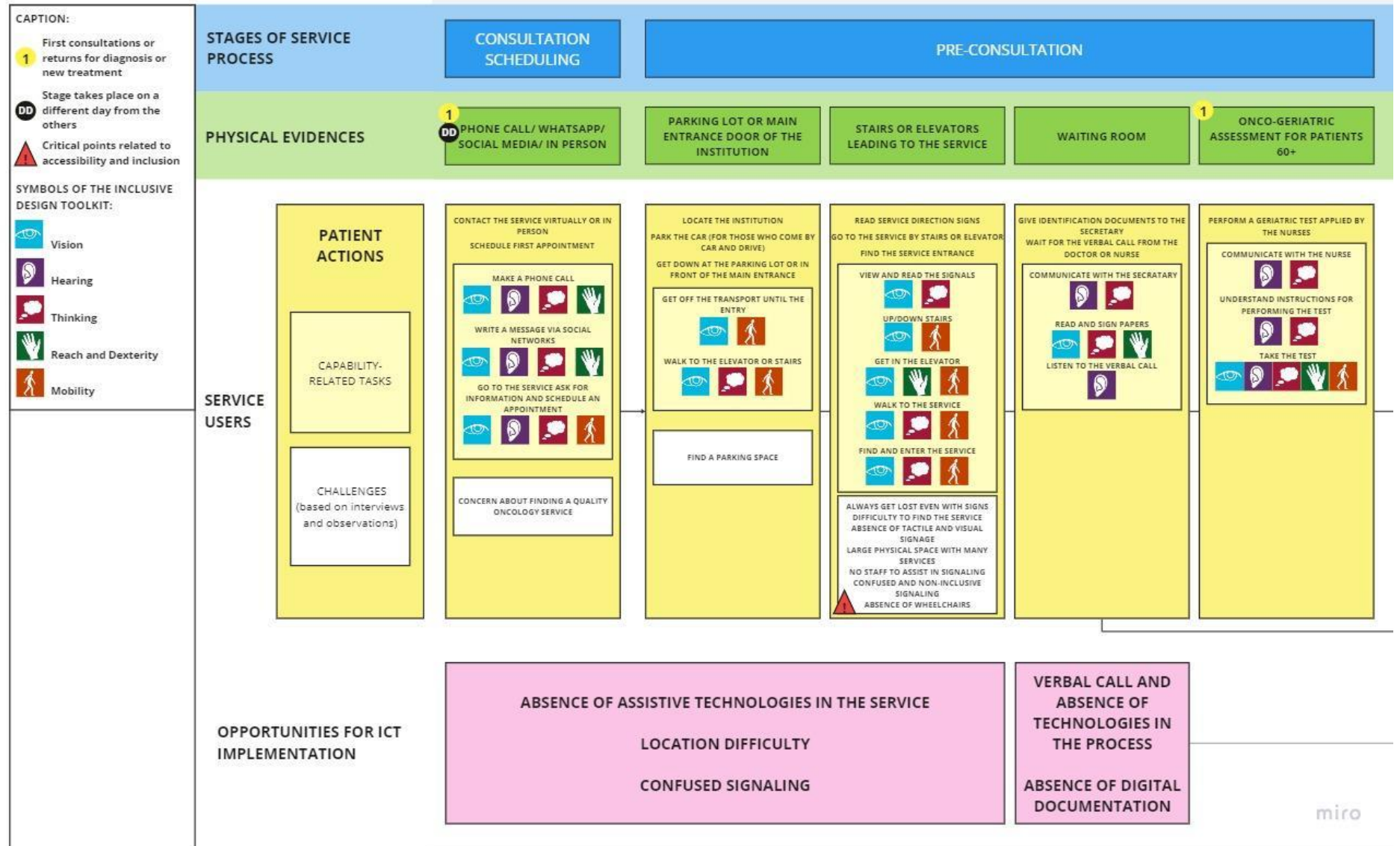
identify prejudice, but the statement that there are no patients with disabilities in the service demonstrates a lack of awareness and training to assist them.

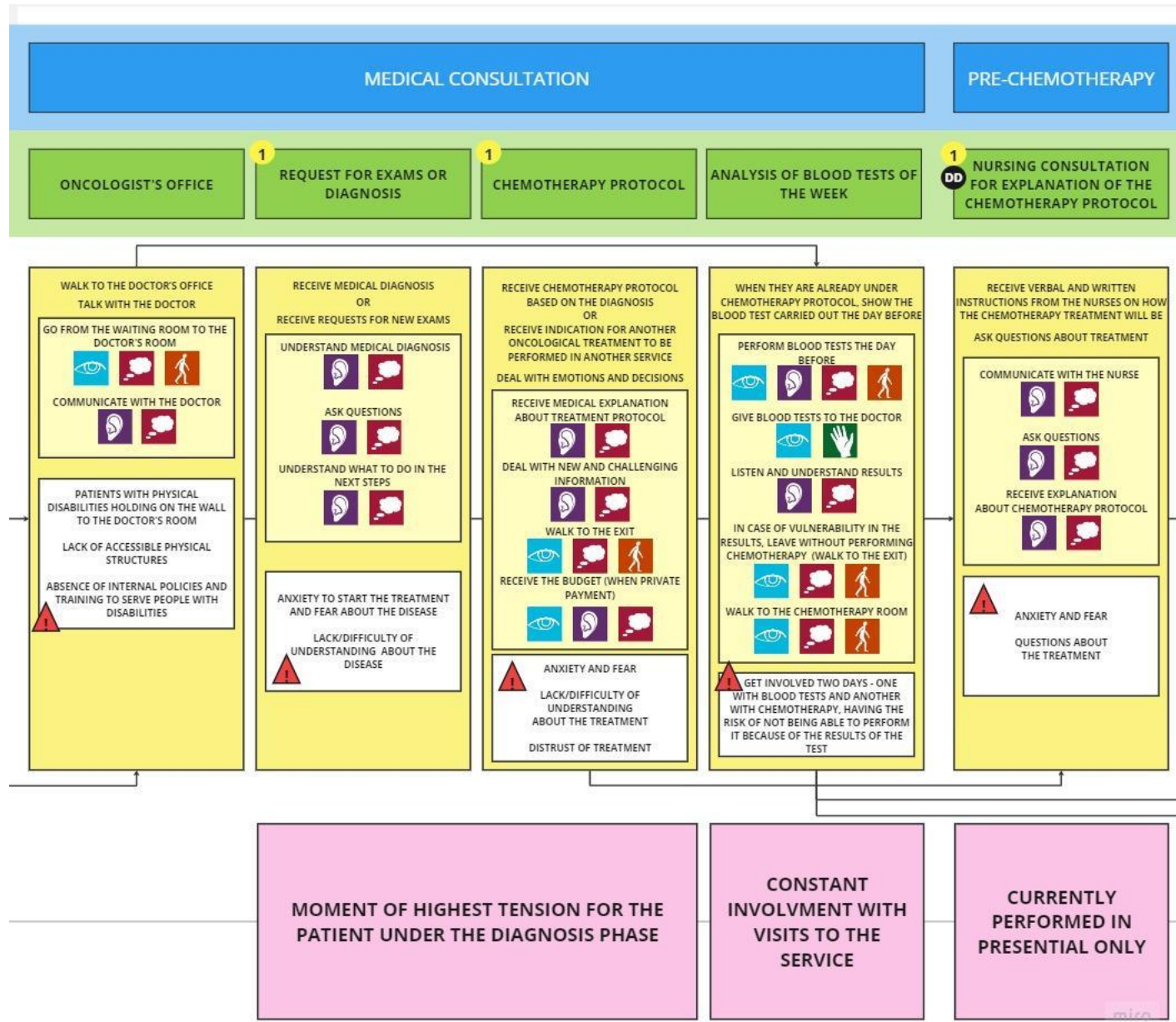
The communication barriers between patients and service professionals may also be related to the perceived attitudinal barriers, since the attitude towards patients with capability loss was not conducive for that patient to fully trust the treatment received. In the case of P3 and P1, both were suspicious of some procedure at the service, and both had cognitive impairments resulting from the treatment. The attitude towards these patients may have disadvantaged the trust process, generating anxiety and confusion.

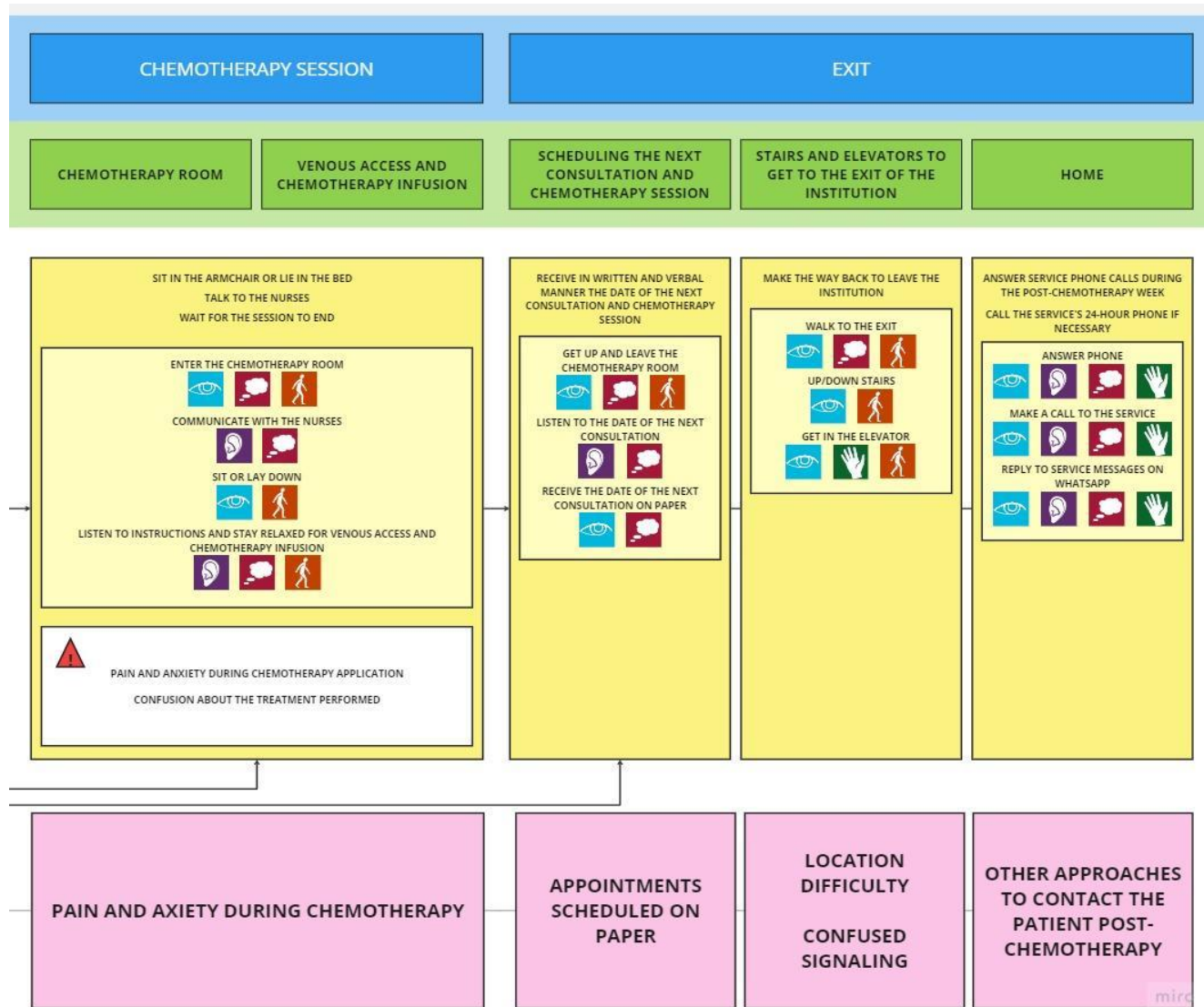
Another issue that can be related to attitudinal aspects is that patients feel very anxious while receiving chemotherapy. Even though this is not the moment in which the patients are most anxious, it is a moment of fragility, which makes them more sensitive. We observed this because in the beginning of the interviews, most patients were suspicious, but during the conversation they started to open up and let out all their distress. We observed the embracement of the nursing team as exemplary. The nurses are tireless and try to cheer the patient up during the difficult time of the chemotherapy session. However, this proved to be a critical moment in attitudinal terms, since each patient is different and requires different attention.

To show the user journey in the outpatient oncology service in more detail, Figure 4 brings the user journey map which highlights the stages of the service process, physical evidence for each of the stages, patients' actions, capability-related tasks required in each of the stages, and barriers based on the interviews and observations, informing the critical points related to accessibility and inclusion. The user journey map also brings opportunities for technologies to be implemented in order to help in the identified critical points related to accessibility and inclusion.

Figure 4 – User journey map through the service







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## 4.2 WORKSHOP

The workshop data was used as a way to improve the propositions designed for the analyzed service, through the perspective of different actors. For data analysis at this stage, two themes emerged from the collected data: solutions for health services; and solutions beyond the services.

### 4.2.1 Solutions for health services

Regarding solutions for health services in general, considering the oncology service, the participants brought up the lack of professional training to deal with PwD as their initial questioning. The creation of an inclusive culture and health education were central points in this discussion. The group of blind and deaf people mentioned they struggle to access parking gates and elevators and to be communicated in case of emergencies. In addition, they mentioned the lack of preparation starting from the reception, where forms need to be read and signed. The problem continues in the consultation, where doctors do not know how to explain the diagnosis to patients with disabilities, who do not understand their situation, in addition to not understanding their treatment in depth, due to the lack of accessible communication resources. These issues were brought up by the specialist and sign language interpreter, who represented what people with hearing impairments discussed in the synthesis stage of the workshop.

*Specialist: The problem starts at the parking gate when you arrive anywhere. In a hospital the same thing. [...] After that, you get to the elevator, you have problems in the elevator, you have problems when you're at the reception, people don't understand, sometimes they ask you to write, to communicate. After that, lack of explanation at all [...] There's a problem with the entire journey.*

A blind participant highlighted that accessibility is much more than having someone fill out a form for them. She commented that, in addition to being

inaccessible, it exposes the patients, who sometimes need to externalize their information to another person, while other people may listen in, because the form is not adapted.

*Blind participant: Because, let's say, I'm ending my treatment now, and then at that moment there will be a mix of emotions for me [...] to talk out loud. And then they say "let me fill it in for you". No! If I have things I want to internalize here yet.*

Both participants with disabilities highlighted the need for health services to make information accessible to give them autonomy. They also highlighted the importance of knowing that not all deaf people know Libras or the language spoken by people without disabilities and that not all blind people know Braille. Therefore, solutions must always be comprehensive, seeking to include diversity, even within a group that we usually judge as equal to each other. Furthermore, participants showed concern for users who may have multiple vulnerabilities, such as people who are both blind and deaf. This condition, compounded by a disease like cancer, makes this person even more dependent on a prepared service.

The PwD group, as well as patients, professionals, and specialists, stressed the importance of integration groups among patients, which could alleviate the emotional burden of the disease. These group meetings could take place according to the user's preference, including an online option. PwD also discussed other digital solutions that could facilitate the service, such as a service application that had a virtual journey map, a pain scale marker, with a user login and password to store information about how they were feeling on the day of the consultation, and a chat available for questions. A cancer patient agreed that this solution would also be helpful for health professionals to remember and update patients' data.

#### **4.2.2 Solutions beyond the services**

Many of the ideas for solutions proposed by the workshop participants went beyond health services, as accessibility and inclusion are concepts that go far beyond the environment of a health service. Therefore, the participants highlighted the

importance of making information about diagnosis accessible in all spheres. Many campaigns are carried out and disseminated universally in digital media, without considering that a blind woman, for example, does not have a description of how she should touch her own breast for the early diagnosis of breast cancer. The materials conveyed in the media are generally visual and do not consider that PwD may not clearly understand the information. In terms of public health, participants with disabilities suggested that all advertising related to health needs to be accessible, both in descriptive terms and in visual terms, in addition to having representation in what is conveyed.

Participants also highlighted the issue of laws. Even though there are laws, quality assurance and inspection are needed. Moreover, the problem related to accessibility in all spheres depends on a change in people's education and public policies, so that society as a whole knows how to deal with and accommodate different needs. Thus, regardless of technologies, deaf participants stated that above all, respect and empathy need to be present. Only this way can other solutions make sense.

Through the results of the first moment of the case study, barriers were found in the oncology service, highlighting critical points related to accessibility and inclusion, and demonstrating that all stages of the service demand capabilities from the users which can compromise access and lead to exclusion. The workshop brought up results related to reflections on the barriers met, considering the experience of PwD. The barriers found in the service are the reality of PwD in several other services and depend on issues that go far beyond. Based on the theoretical background on inclusive design, accessibility, and ICTs, and on the data collected in the two instances of the case study, the results of the study and opportunities for implementing ICTs in the context under analysis will be discussed below.

## **5 DISCUSSION**

As seen in Figure 4, all stages of the oncology service require user capabilities, whether related to vision, hearing, cognitive aspects, reach and dexterity, and mobility.

Therefore, from the moment that critical points and barriers are found in these stages, it is possible that the demands of the service are sometimes greater than the capabilities of the users (PERSAD; LANGDON; CLARKSON, 2007). So, understanding that technologies may help with problems in the health area, bringing innovative solutions to the context (MASTRONARDO et al., 2021; HALEEM et al., 2022), this section will discuss the opportunities for implementing ICTs in the analyzed service.

Table 4 brings in detail the suggestions for improvements based on ICT applications for the analyzed service.

**Table 4 - Suggestions for improvements based on ICT implementation for the analyzed service**

Opportunities based on the case study	Suggestions of ICT implementation for the context of the case study	How it would be in practice
Difficulty finding the service  Signage with too much and confusing information  Absence of tactile and visual signage  Large physical space with many services  No staff to assist in signaling  Confused and non-inclusive signaling	Digital wayfinding projects:  - Touchscreen interfaces (kiosks)  - Customized mobile health application for the service (guided maps)	- Touchscreen interfaces should be implemented in each of the entrances, so that the user could also be guided on how to reach their destination service.  - A mobile application could guide the patient on how to get to the service they want. A guided map of the institution could be inserted into the app, which users could access in case of trouble with directions.
Verbal call	Visual and audible call screens	- In spite of being conventional technologies, they are not present in the service where they could be allies in calling users in the reception room.
Absence of digital and inclusive documentation	Digital documentation on tablets and other devices (documents could be included in the customized mobile health application for the service).	- Digital availability of contracts and documents for reading and signature, with accessibility features for screen reading, captions and different ways of inserting data.  - The service application could have patient documents and forms attached.
Constant involvement with visits to the service	Customized mobile health application for the service:  - Telemedicine  - Video consultation	- Implementation of a service app that would allow the login of each patient and that could be a channel for telemedicine, video consultations, live chats, and connection to wearables for remote monitoring, with all the patient's data, allowing real-time alerts for the health professionals.

	<ul style="list-style-type: none"> <li>- IoT based system for monitoring - wearable devices</li> <li>- Big data for real-time alert</li> <li>- Live chats and video calls for better communication</li> </ul>	- Patient monitoring could also be carried out through the application in the post-chemotherapy week and not only through conventional calls to the patient.
Pain and anxiety during chemotherapy	<p>Virtual reality solutions</p> <p>Conventional ICTs such as smart televisions</p>	<ul style="list-style-type: none"> <li>- Implementation of virtual reality to reduce pain and anxiety during chemotherapy.</li> <li>- Implementation of conventional technologies, more modern than those available in the service such as smart TVs that allow the patients to watch programs that distract them during chemotherapy.</li> </ul>
<p>Anxiety to start the treatment and fear about the disease and treatment</p> <p>Lack/difficulty of understanding about the disease and treatment</p> <p>Distrust of treatment</p> <p>Personal organization of paper documents</p> <p>Appointments scheduled on paper</p>	<p>Customized mobile health application for the service in order to:</p> <ul style="list-style-type: none"> <li>- Organize patient history, medical records, appointment schedules and all patient information</li> <li>- Provide patient education</li> <li>- Provide relationship among patients</li> </ul>	<ul style="list-style-type: none"> <li>- The app would also organize patient history, medical records, appointment schedules, and all patient information. In addition, it could be a patient education mechanism, increasing understanding about the disease and treatment through playful resources.</li> <li>- The app could also be a communication channel between patients, in order to connect and share experiences (means of scheduling meetings between patients).</li> <li>- The app could have a feature where patients could write their feelings and even have a pain scale marker.</li> </ul>

Elaborated by the authors (2023)

The opportunities for ICT implementation matter to ID, being related with ID principles (CABE, 2006), since: the environments are not designed to consider all people, making access difficult, especially for those with disabilities, who may be excluded from access (contradicting the ID principle of providing environments convenient and enjoyable for everyone, despite the existence of NBR 9050 (ABNT, 2020)); not all people can hear the call of health professionals, nor read and sign papers and service documents (noting that the principles of knowing differences and diversity, offering different options for accessing information are not taken into account); there is a lack of flexibility for the user who is physically and emotionally vulnerable due to constant involvement with the service (contradicting the ID principle of flexibility in use); and anxiety to start the treatment, fear of the disease, difficulty in understanding the process, distrust of the treatment, and confusion in the organization of documents about the treatment (which means that sometimes the service does not offer different options for different needs).

So, we observe the potential of ICTs to collaborate in improving aspects of accessibility and expanding inclusion, bringing advances to ID research. More than the application of the technology itself, what matters most to us is the role of these ICTs for ID and their potential for improving accessibility aspects and expanding inclusion in the analyzed service. This study advances the discussion of ID bringing technologies as opportunities to mitigate critical points related to accessibility and inclusion throughout the journey of users through a health service. Although we have brought a series of ICTs that can contribute to the context under analysis, the majority of solutions can be concentrated in a mobile application, which makes the service more accessible and increases inclusion as they:

- Allow customization options for disabilities, gamification options depending on needs, multiple sense options, adaptation for screen reading, captions, voice command, digital reading and signature, and adaptation to individual needs. ICTs have customization versatility to meet different needs (THANGAVEL; MEMEDI; HEDSTRÖM, 2022; UNESCO, 2023). Therefore, they are a good option for mitigating persistent problems of accessibility and inclusion in services, because at the same time that they can be customized for better digital accessibility (IPEDIS, 2023; WAI, 2023), they bring solutions to the health context (GAGNON et al., 2012).
- Strengthen patients' autonomy by allowing them to manage their own health data, to understand the disease and the treatment, to go to the service by themselves, and to make connections with other patients. ICTs give autonomy to the users, even more to those with limitations (such as PwD, the elderly, people with reduced mobility, cancer patients and other comorbidities), who depend on others. Being able to communicate with the doctor virtually, having their health controlled remotely, having access to their health data, medical records, and history at the service, being able to find the service without needing help, having the opportunity to share with other patients to improve treatment anxiety, etc. gives the users independence. This is in line with previous studies

that relate technologies with health autonomy for users with limitations (ACIEM; MAZZOTTA, 2013; SCHLOMANN et al., 2020). Although ID advocates that the solutions be easy to use by all people, which makes the user more autonomous, many studies are focused on the inclusive design of products (van Der CAMMEN et al., 2016; PEREIRA; HEITOR; HEYLIGHEN, 2018). In the scope of health services, giving patients autonomy is also extremely important (LEE; LIN, 2010), as it gives them a sense of belonging, and thus, inclusion in their treatment process.

- Give patient options of choice for remote consultations when possible, allowing them to receive healthcare from home (particularly important for patients with mobility limitations). From the ID perspective, giving users the choice of being able to consult via telemedicine means offering options when a single solution is not capable of covering all people (CABE, 2006). Of course, for chemotherapy sessions, patients need to visit the service in person, but some appointments could be avoided with an online screening. The literature shows significant advantages in access to health by patients with disabilities when using telehealth, so physical access barriers are reduced (DAVIS et al., 2014; HATCHER-MARTIN et al., 2019).
- Allow privacy. With individualized logins, certain data can only be accessed by the doctor and the patient, for example. In addition, the fact that the patient, regardless of the disability, does not need to depend on other people to fill in personal information helps with privacy, since when handling the technology, this patient will be able to fill in his data without disclosing them to a professional who they do not feel comfortable with or around other patients. As much as privacy is not a unique concern of PwD, many studies (e.g. KAIRY et al., 2021; MINEN et al., 2021) have shown that it is important for users with limitations regarding personal data in the digital context. Other studies have also stated the importance of privacy in health services for this public (e.g. KHANLOU et

al., 2018), relating privacy to quality of life, well-being, empowerment and inclusion.

In this perspective, technologies have the potential to improve accessibility and expand inclusion in a health service, as long as they are designed to be implemented in the right context, causing the right impact, according to specific needs. Furthermore, for all this to work, users with limitations (PwD, people with reduced mobility, the elderly, more vulnerable patients due to diseases such as cancer, etc.) need to know how to use ICTs. Otherwise, patients will find even more demands on their capabilities, which could further complicate access (PERSAD; LANGDON; CLARKSON, 2007). This is because we are talking about a product (technology) that needs to solve an accessibility problem in a health service. Then, this product also depends on the look of inclusive design, so that it is decisive in the context under analysis. As the intention is to provide accessibility for patients in the service, the technologies must follow an accessibility standard, with structures designed for patients with visual, hearing, cognitive, reach and dexterity, and mobility losses (KÖNIG-KLEVER et al., 2023) (ARTICLE 1).

However, for the implementation of ICTs to make sense, there must be a culture of inclusion in the institution and the service. All of this is worthless if the organization does not have internal policies aimed at accessibility for patients with disabilities. And that is where the programmatic barriers found in the service come in. If the service does not regulate a differentiated look at these patients, it will be difficult for strategies to be implemented in order to include more patients in the service. First, there must be recognition of the national laws and regulations for PwD (BRASIL, 2015; ABNT, 2020). We noticed that some situations depend on interventions prior to the implementation of technologies. We observed inadequacies in the implementation of NBR 9050/2020 standards, such as the lack of floors and tactile signs, the lack of a Libras interpreter, the absence of crutches or handrails on the walls, and attitudinal aspects that reveal a lack of preparation by professionals to receive and deal with patients with disabilities. This finding is in line with the study by Agaronnik et al. (2019b), which shows that healthcare teams are unprepared to deal with PwD. Nevertheless, it cannot be solved

by technology alone, but depends on a more macro action, coming from the institution and the service, to be able to understand and meet all existing needs (MEDEIROS; ACIOLY; SILVA, 2015). We perceive technologies as allies in the process of including PwD in the service, but they need full support, which today is non-existent in the institution.

In addition, ID values solutions that can reach everyone (BURGSTAHLER, 2001; PATTISON; STEDMON, 2006; GOODMAN-DEANE et al., 2014; GOMES; QUARESMA, 2018). However, we recognize that it is very challenging to come up with a solution that meets everyone's needs. When this is not possible, different solutions with different accessibility requirements must be implemented, so that as many people as possible have easy access and receive a quality service (IDRC, 2023).

Therefore, each solution should be explored and thought out with a holistic view, trying to reach as many people as possible. For example, the service signaling problem can be solved with ICTs, as long as they do not present the same problems that signs present today. Signposts and folders with the institution's map do not read in Braille, nor are they designed for deaf people who cannot read Portuguese. There is no resource designed for those who have some type of capability loss. Therefore, technologies must also look into these aspects. So the implementation of a customized mobile health application needs to contemplate all types of communication. And, if it is not possible to meet the requirements for everyone, it is imperative that other solutions be thought out, in order to meet different groups.

## **6 CONCLUSIONS**

This study aimed at (i) identifying the critical points of the patient's journey regarding accessibility and inclusion in a Brazilian outpatient oncology service, (ii) understanding the needs of people with disabilities and possible solutions for the health service according to their needs, and (iii) discussing the potential of ICTs to improve aspects of accessibility and expand inclusion in the service. For this, a case study was carried out, with interviews and non-participant observations in an oncology service

and a workshop that involved PwD, patients, companions, specialists, and health professionals.

Barriers related to accessibility and inclusion in the service were identified, related to architectural, communicational, methodological, instrumental, programmatic, and attitudinal aspects. A user journey map identified that all stages require some capability from the user whether related to vision, hearing, cognitive aspects, reach and dexterity, and mobility. The identified critical points and barriers related to inclusion and accessibility may cause exclusion at certain touchpoints. In this way, opportunities were identified for the implementation of technologies in the context under analysis, mainly related to the difficulty of orientation and location in the service, signs with a lot of information, lack of accessible signs for multiple disabilities, large environment with many services, verbal call, lack of comprehensive documentation, constant visits to the service, anxiety and pain during chemotherapy, anxiety about the disease and treatment, personal organization of documents and appointments, and lack of confidence and understanding about the treatment.

Although many solutions are important and relevant to the context under analysis, the solution was mainly focused on a customized mobile health application for the service that can rely on telemedicine, video consultation, IoT based system for monitoring - wearable devices, big data for real-time alert, live chats and video calls for better communication, guided maps (digital wayfinding project), patient education, medical history, records, and scheduling appointments. In this way, the ICT proposal brings advances to inclusive design by solving the critical points related to accessibility and inclusion in the service, allowing customization options for disabilities, giving patients choice, strengthening patients' autonomy, and allowing privacy. In addition, we highlight that the implementation of ICTs as a solution to accessibility problems in the health service depends on these technology structures in relation to digital accessibility for users with limitations, as well as an inclusive culture in the service.

In addition, the study focused on the reality of a Brazilian health service. Therefore, the possibilities of solutions discussed were those applicable to the context under analysis, considering that Brazil is an underdeveloped country, which is still in initial stages with regard to innovative technologies compared to other socioeconomic

realities. In this perspective, we emphasize that many ICT solutions depend on a financial outlay by the health service which, despite being private, has other financial priorities. Thus, we highlight the importance of partnerships between companies and universities for research, development and implementation of innovative solutions in the health context.

This study has the potential to inspire other similar health services in solving their problems related to accessibility and inclusion through ICTs. Some aspects serve as a lesson for the implementation of ICTs in similar services: (i) the opportunities for an effective contribution of technologies, so that they do not impose more barriers to patients, (ii) give the patient autonomy, privacy, and choice options in the health service through ICTs, and (iii) look more deeply at all aspects of accessibility, seeking to organize the service in terms of accessibility and inclusion before thinking about an ICT solution.

This study has some limitations. The first is that the interviews with the patients were carried out in the service during chemotherapy. As the nurses were always present, many patients may have felt inhibited from talking about critical points observed in the service, as well as from suggesting improvements. However, this limitation did not harm the results, because the observations and the workshop showed many gaps not mentioned by the patients in the interviews. As another limitation, we can cite the lack of use of a scale that could quantitatively measure the exclusion of users in the different touchpoints of the service. However, based on the qualitative data, it was possible to carry out analyzes that showed relationships between capability and demand in the analyzed service.

Future studies can carry out quantitative analyzes regarding the theme of accessibility and inclusion in a health service. In addition, future research could take users with different disabilities through the user journey, in order to make the understanding of critical points more personalized for different disabilities and needs. Considering the lack of ICTs in the analyzed service, future research could also design and apply a mobile application to the service, which would be personalized and help in the identified aspects.

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## 5 CONSIDERAÇÕES FINAIS

Neste capítulo serão apresentadas as considerações finais da dissertação, bem como as contribuições acadêmicas e práticas do trabalho e as oportunidades para pesquisas futuras.

A realização do trabalho iniciou a partir da questão de pesquisa: como as TICs podem contribuir para melhorar aspectos de acessibilidade e ampliar a inclusão em um serviço ambulatorial de oncologia, à luz do design inclusivo? Para isso, foram realizados uma revisão sistemática da literatura e um estudo de caso. Na revisão, o foco foi o entendimento das estruturas de TICs para atender às necessidades de usuários com limitações. O estudo de caso foi realizado em duas partes. Em um primeiro momento foram realizadas entrevistas em profundidade e observações não participantes em um serviço ambulatorial de oncologia, de maneira a entender a jornada de pacientes oncológicos e os pontos críticos relativos a acessibilidade e inclusão. Em um segundo momento, um workshop foi realizado de forma a entender algumas necessidades específicas de pessoas com deficiência e delinear soluções em TICs que pudessem melhorar os aspectos de acessibilidade e ampliar a inclusão no serviço analisado.

Os resultados da pesquisa mostram que, para que TICs possam auxiliar em aspectos de acessibilidade de serviços de saúde e incluam pacientes com todas as necessidades existentes, é preciso que elas sejam desenvolvidas de acordo com as necessidades dos usuários. A revisão sistemática delineou as estruturas que precisam ser consideradas quando pensamos em TICs para usuários com limitações, pensando em deficiências, pacientes com doenças crônicas, idosos, pacientes com mobilidade reduzida, e todas as condições que podem acometer um usuário e torná-lo mais vulnerável. As estruturas identificadas precisam ser consideradas pelos designers de tecnologias em saúde para que usuários com limitações consigam utilizá-las.

Em relação à jornada do usuário pelo serviço de oncologia analisado, barreiras foram identificadas nas perspectivas arquitetônica, comunicacional, metodológica, instrumental, programática e atitudinal. Algumas dessas barreiras podem ser resolvidas por meio de TICs, sendo que um aplicativo personalizado para o serviço foi

a solução principal discutida para o contexto de análise, podendo reunir soluções em telemedicina, consultas por vídeo, sistema de monitoramento remoto, alertas em tempo real, chats virtuais, mapas de orientação, educação do paciente, agendamento de consultas, histórico médico e prontuário. Essa solução contribui para o contexto analisado, de modo que permite opções de customização para deficiências, dá ao paciente opções de escolha, permite privacidade e aumenta a autonomia do paciente – pontos que estão de acordo com o design inclusivo.

Além disso, é importante destacar que no workshop mostrou-se necessária a resolução de algumas problemáticas anteriores à implementação de tecnologias, de maneira que exista nas instituições de saúde uma cultura de inclusão. Isso foi de encontro com os dados encontrados no serviço analisado, que não possui diretrizes de políticas de atendimento à pessoa com deficiência, e desconhece a existência desses pacientes no serviço.

De maneira geral, com os achados desta dissertação, a pergunta de pesquisa pode ser respondida da seguinte forma: para que as TICs possam contribuir para melhorar aspectos de acessibilidade e ampliar a inclusão em um serviço ambulatorial de oncologia, é necessário que sejam estruturadas de acordo com as necessidades dos usuários com deficiência (acessibilidade tecnológica), sejam implementadas de maneira a resolver pontos críticos de acessibilidade e inclusão do serviço (acessibilidade no serviço), e façam parte de uma cultura inclusiva, que precisa começar muito antes de sua aplicação. Como foi visto, a localização no serviço é um ponto crítico de acessibilidade e inclusão de pacientes. A tecnologia auxilia a resolver essa problemática por auxiliar esse paciente a chegar onde precisa, resolvendo uma questão de acessibilidade no serviço (mapa virtual de orientação), e por poder ser estruturada de acordo com as necessidades de qualquer usuário (exemplo, para um usuário cego, o mapa pode ser guiado por voz, para um usuário surdo, o mapa pode ter opção de legenda e interpretação de sinais etc.). A tecnologia apresenta, assim, uma versatilidade e adaptabilidade às necessidades, que outras soluções poderiam não apresentar. E para que tudo isso ocorra, o serviço precisa estar alicerçado em uma cultura de inclusão, que considere as deficiências prévias às doenças, as

deficiências que surgem ou se intensificam pelas doenças, e as múltiplas vulnerabilidades que podem acometer os pacientes.

Além disso, destacamos que, por vezes, uma única solução não conseguirá abarcar a todos os usuários, porque mesmo usuários de um mesmo grupo de deficiências podem ter necessidades diferentes. Por isso a importância de desenhar tecnologias e serviços sempre pensando em soluções que abarquem o maior número de pessoas possível ou em diferentes soluções que também cumpram esse papel.

## 5.1 CONTRIBUIÇÕES ACADÊMICAS E PRÁTICAS

Podem ser destacadas contribuições acadêmicas por meio do desenvolvimento desta dissertação, contribuindo para o mapeamento do estado da arte no tema de design inclusivo. Esse trabalho avançou no estudo da temática, uma vez que poucas pesquisas relacionam o design inclusivo com a área da saúde e nenhum estudo havia relacionado design inclusivo, serviços de saúde e tecnologias da informação e comunicação. O trabalho permitiu a correlação entre essas três temáticas e o design inclusivo como pano de fundo para o design de TICs, para o design de serviços inclusivos e para a utilização de TICs de maneira a tornar serviços de saúde mais inclusivos a todos os pacientes, independente da condição de limitação.

Esta dissertação trouxe avanços também no que tange ao entendimento de um serviço inclusivo. Os resultados foram além dos princípios preconizados pelo design inclusivo, porque além de as soluções pensadas colocarem as pessoas no centro do processo de design, reconhecerem a diversidade e as diferenças, oferecerem opções para acomodar diferentes necessidades, fornecerem flexibilidade e proporcionarem ambientes convenientes e agradáveis para todas as pessoas, proporcionam aos usuários aspectos mais específicos que podem não estar diretamente relacionadas com a inclusão, mas que fazem o usuário se sentir parte do serviço que lhe é prestado. A adequação aos princípios do design inclusivo mostrou ir muito além do que somente pensar em acessibilidade no serviço de saúde. As soluções pensadas têm o potencial de proporcionar ao usuário, não somente ambientes, tecnologias e serviços que se adequem às suas necessidades, mas o sentimento de que podem conviver

normalmente em sociedade, sem barreiras, com autonomia, com privacidade, com opção de escolha, com entendimento, com discernimento e com engajamento.

Projetar soluções inclusivas é muito além do que adequação às normas, do que personalização para atender às deficiências, ou do que proporcionar espaços e tecnologias acessíveis. Este trabalho mostrou que projetar soluções inclusivas significa fazer tudo isso, para que o paciente com deficiência, com múltiplas vulnerabilidades, possa se sentir contemplado, seguro e respeitado nos serviços de saúde, recebendo toda a informação necessária para tomar decisões sobre seu próprio corpo e sobre sua saúde.

Além de contribuir com a área acadêmica, o estudo apresenta contribuições práticas, que podem auxiliar serviços de saúde a se tornarem mais acessíveis e inclusivos para todas as pessoas. Para isso, após a defesa da dissertação e os ajustes solicitados pela banca avaliadora, os resultados da pesquisa serão divulgados ao serviço, de maneira a fazer uma devolutiva sobre os pontos críticos identificados e soluções propostas. Essa devolutiva ocorrerá de maneira presencial aos dois médicos gestores e responsáveis técnicos do serviço, de forma didática, por meio da utilização da plataforma Miro, com esquemas de fácil visualização. Espera-se um momento de troca e auxílio por parte dos pesquisadores no que for de interesse de implementação dos gestores.

Além disso, no workshop os participantes demonstraram interesse sobre os resultados da pesquisa, principalmente os pacientes do serviço analisado. Dessa forma, as soluções de melhoria pensadas serão também repassadas aos pacientes participantes do estudo que se mostrem interessados.

## 5.2 OPORTUNIDADES PARA PESQUISAS FUTURAS

Pesquisas futuras podem propor o design TICs para usuários com limitação com base nas estruturas encontradas na revisão sistemática, de maneira que estas possam ser implementadas de forma prática, permitindo o surgimento de outras estruturas, além das abordadas pelos estudos da revisão sistemática. Além disso, estudos poderiam ser desenvolvidos de maneira a mensurar o aumento da inclusão

em serviços de saúde pela implementação de TICs, buscando entender de maneira aplicada o quanto tecnologias podem ser benéficas para diminuir os pontos críticos e barreiras de acessibilidade nos serviços de saúde.

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## APÊNDICE A – PROTOCOLO DA REVISÃO SISTEMÁTICA DA LITERATURA COM BASE NAS ETAPAS PROPOSTAS POR ARKSEY E O'MALLEY (2005)

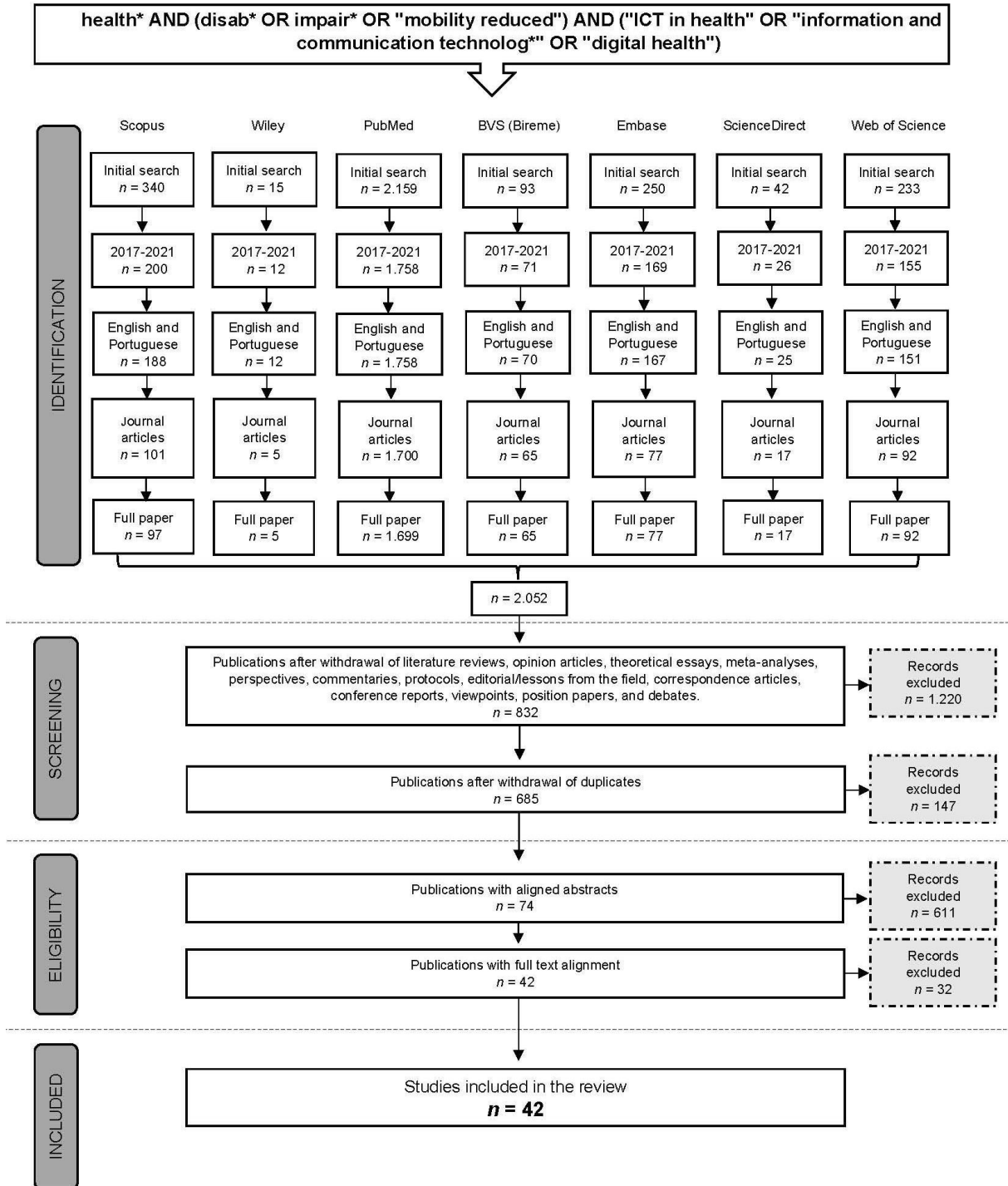
<b>(I) IDENTIFICAR AS QUESTÕES DE PESQUISA</b>	
<b>Questão 1</b>	<b>Como as TICs em saúde são estruturadas para atender usuários com limitação?</b>
Questão 1.2	Quais contribuições as tecnologias trouxeram para problemáticas de acessibilidade e inclusão no contexto de saúde?
Questão 1.3	Quais foram os maiores desafios relacionados à implementação das tecnologias?

<b>(II) IDENTIFICAR ESTUDOS RELEVANTES</b>	
<b>Bases de dados</b>	Scopus, Wiley, PubMed, BVS (Bireme), Embase, Science Direct, Web of Science
<b>String de busca geral</b>	health* AND (disab* OR impair* OR "mobility reduced") AND ("ICT in health" OR "information and communication technolog*" OR "digital health")
<b>String de busca Scopus</b>	ABS ( health* AND ( disab* OR impair* OR "mobility reduced" ) AND ( "ICT in health" OR "information and communication technolog*" OR "digital health" ) )
<b>String de busca Wiley</b>	"health* AND (disab* OR impair* OR "mobility reduced") AND ("ICT in health" OR "information and communication technolog*" OR "digital health")" in Abstract

<b>String de busca PubMed</b>	(health*[Abstract] AND (disab*[Abstract] OR impair*[Abstract] OR "mobility reduced")[Abstract] AND ("ICT in health"[Abstract] OR "information[Abstract] AND communication technolog*"[Abstract] OR "digital health")[Abstract])
<b>String de busca BVS (Bireme)</b>	(ab:(health* AND (disab* OR impair* OR "mobility reduced") AND ("ICT in health" OR "information and communication technolog*" OR "digital health")))
<b>String de busca Embase</b>	health*:ab AND (disab*:ab OR impair*:ab OR 'mobility reduced':ab) AND (('ict in health':ab OR information:ab) AND 'communication technolog*':ab OR 'digital health':ab)
<b>String de busca Science Direct</b>	<p>health AND ((disability OR disabled) OR (impair OR impairment) OR "mobility reduced") AND ("ICT in health" OR "information and communication technology" OR "digital health")</p> <p>*Base não permite a utilização de asteriscos, nem mais do que 8 operadores booleanos. Por isso, o string foi montado de maneira diferente dos demais.</p> <p>**Base não permite busca das palavras somente nos abstracts, por isso foi buscado no campo "Title, abstract or author-specified keywords".</p>
<b>String de busca Web of Science</b>	Abstract: health* AND (disab* OR impair* OR "mobility reduced") AND ("ICT in health" OR "information and communication technolog*" OR "digital health")
<b>Período de realização da busca</b>	Maio de 2022
<b>Critérios de inclusão</b>	Apenas artigos publicados em periódicos, publicados na íntegra, com publicação de 2017 a 2021 (no período da busca), no idioma inglês e português.
<b>Critérios de exclusão</b>	<p>Artigos em duplicação</p> <p>Artigos que apresentam revisões de literatura, artigos de opinião, ensaios teóricos, meta-análises, perspectivas, comentários, protocolos, editoriais/lições da área, artigos para correspondência, relatórios de congressos, pontos de vista/pessoais, documentos de posição e debates.</p>

	<p>Artigos que não tratam de tecnologias em um contexto de acessibilidade e limitação.</p> <p>Artigos que não tratam do contexto da saúde.</p> <p>Artigos que não tratam do contexto das tecnologias.</p>
<b>BUSCA INICIAL</b>	
<b>Scopus</b>	340 artigos
<b>Wiley</b>	15 artigos
<b>PubMed</b>	2.159 artigos
<b>BVS (Bireme)</b>	92 artigos
<b>Embase</b>	250 artigos
<b>Science Direct</b>	42 artigos
<b>Web of Science</b>	233 artigos

## (III) SELECCIONAR ESTUDOS

Fluxograma adaptado de PRISMA (MOHER *et al.*, 2015)

#### (IV) MAPEAR OS DADOS

Análise qualitativa dos dados, organizados em uma planilha com as seguintes categorias: título do artigo; ano de publicação; nomes dos autores; local de publicação; periódico publicado; objetivo; procedimento de pesquisa utilizado; tema principal; público-alvo de análise; limitações identificadas; tecnologias aplicadas/trabalhadas no artigo; estruturas para atender usuários com limitação; contribuições da aplicação para a acessibilidade e a inclusão; desafios de implementação; resultados da pesquisa; e relações com o design inclusivo.

#### (V) REUNIR, RESUMIR E RELATAR OS RESULTADOS

1. Visão geral dos estudos em relação às tecnologias aplicadas e limitações identificadas.
2. Análise temática da questão sobre contribuições com cinco temas e 13 subtemas oriundos dos dados.
3. Análise temática da questão sobre barreiras com um tema principal, 12 subtemas e nove categorias referentes aos subtemas oriundos dos dados.
4. Análise temática da questão principal sobre as estruturas das tecnologias, com quatro temas e 13 subtemas do Web Accessibility Initiative (WAI, 2019), e com seis temas e 12 subtemas oriundos dos dados.

\*Mais detalhamentos diretamente no artigo.

## APÊNDICE B – DIÁRIO DE CAMPO DA OBSERVAÇÃO NÃO PARTICIPANTE

**Objetivo:** observar os pontos críticos relacionados à inclusão e à acessibilidade do paciente ao longo de sua jornada (desde o momento que chega no serviço até o momento que deixa o local), como forma de identificação de oportunidades de melhoria. Além disso, observar todos os espaços da instituição e do serviço em relação às adequações e inadequações em termos de acessibilidade e inclusão.

<p style="text-align: center;"><b>Identificação</b></p> <p>O que está sendo observado, detalhamento do local e das pessoas, data e hora. Atentar para a estrutura em termos de demandas do serviço, e atentar para as capacidades dos usuários que o utilizam, de modo a notar as possíveis barreiras concernentes à acessibilidade e à inclusão.</p>	<p style="text-align: center;"><b>O que aconteceu</b></p> <p>Fatos, descrição de diálogos, descrição de situações ocorrentes percebidas pelos pesquisadores.</p>	<p style="text-align: center;"><b>Evidências coletadas</b></p> <p>Fotografias e gravações que comprovem o que aconteceu.</p>	<p style="text-align: center;"><b>Impressões</b></p> <p>O que senti, pensei ou deduzi a partir do que observei. Dificuldades, barreiras, pontos críticos, facilidades, pontos positivos etc.</p>	<p style="text-align: center;"><b>O que ainda preciso esclarecer mais</b></p> <p>A partir do que foi observado, existe ainda alguma dúvida ou questionamento?</p>

Outros pontos a serem observados para auxiliar na realização e visualização da jornada do usuário no serviço:

- a) Quais as possíveis etapas que o paciente precisa passar desde sua chegada no serviço até sua saída? Quais as “tarefas” o paciente precisa cumprir em cada uma dessas etapas?
- b) Quais as interações existentes ao longo do atendimento? Quais os profissionais-chave envolvidos?
- c) Quais as principais dificuldades enfrentadas pelos pacientes no serviço em termos de acessibilidade?
- d) Quais as demandas do serviço sobre as capacidades dos usuários?
- e) Quais as adequações e inadequações da instituição e do serviço em termos de acessibilidade?

## APÊNDICE C – ROTEIRO DA ENTREVISTA EM PROFUNDIDADE COM PROFISSIONAIS ENVOLVIDOS NO SERVIÇO

Objetivo: Verificar a percepção dos profissionais sobre o serviço no qual atuam, evidenciar sua compreensão sobre aspectos de acessibilidade e inclusão dos pacientes oncológicos no serviço, e entender de maneira mais detalhada da jornada dos usuários pelo serviço.

Participantes: Profissionais do serviço de oncologia

Perfil do respondente:

Função: \_\_\_\_\_

Tempo de atuação no serviço: \_\_\_\_\_

### **Questões gerais sobre o fluxo do serviço e jornada do paciente:**

- a) Como você percebe a estruturação do serviço (desenho do serviço)? Em termos de processo, como você percebe a sequência do serviço?
- b) Você poderia descrever o funcionamento do serviço: qual o fluxo de atendimento, desde a chegada do paciente até sua saída? Especifique a jornada e possíveis etapas percorridas dependendo do tipo de atendimento recebido.
- c) Como você percebe o atendimento prestado? Você acredita que todos os pacientes têm experiências positivas com o serviço recebido?
- d) Como você se sente atuando neste serviço de saúde?

### **Questões específicas concernentes à acessibilidade e à inclusão:**

Introdução: explicar ao participante o contexto que está sendo explorado pelos pesquisadores, a fim de ambientá-lo para a resposta às perguntas.

Sabemos que o câncer e seus tratamentos relacionados podem gerar uma série de limitações ao paciente. Deficiências podem ser causadas em virtude da patologia e do tratamento. Sabe-se também que pessoas que já se encontram em situação de vulnerabilidade antes do diagnóstico e tratamento de câncer podem ser acometidas pela doença. Por exemplo, PcD, idosos, gestantes, pessoas obesas etc., que enfrentam limitações permanentes, temporárias ou momentâneas e mobilidade reduzida podem também ter o diagnóstico de câncer e enfrentarem ainda mais

barreiras. Nesse contexto, esse trabalho está explorando as possíveis demandas do serviço sobre as capacidades dos usuários, de maneira a entender em quais momentos da jornada pode existir algum tipo de exclusão. As demandas consistem nos atributos do serviço, enquanto que as capacidades são os atributos dos usuários e consistem em capacidades sensoriais, capacidades motoras e capacidades cognitivas.

Isso tudo influencia em quanto o usuário entenderá o serviço e conseguirá interagir para receber o atendimento (**mostrar imagem interação com o produto/serviço**). Os indivíduos podem ser excluídos do serviço quando suas capacidades são inferiores às demandas do serviço (**mostrar imagem da teoria da capacidade e demanda**). Com o entendimento dessas questões, serão propostas soluções com base em TICs, e com o olhar do design inclusivo. Diante disso, algumas perguntas em relação ao serviço foram realizadas.

a) Você acredita que a instituição e o serviço estão adequados em termos de acessibilidade aos pacientes oncológicos?

b) Conte sobre a prática de atendimento a pacientes com deficiência no serviço. O serviço conta com pacientes cegos, surdos, com deficiências de mobilidade e cognitivas?

c) Existe alguma preocupação prioritária em relação ao atendimento desses pacientes?

e) Na sua percepção como você enxerga a perda de capacidades pelos diferentes perfis de pacientes oncológicos no serviço (considerando audição, pensamento, destreza e alcance, e mobilidade)? No que se encontra a maior dificuldade em termos de barreiras de acessibilidade?

f) Como é o acesso físico ao serviço? Contempla pessoas com deficiência e/ou mobilidade reduzida? Possui adaptações e instalações acessíveis e adequadas? (pensemos em todas as condições limitantes existentes, e como os aspectos físicos estão adequados, por exemplo: assentos de uso preferencial sinalizados, espaços e instalações acessíveis; adequações de acordo com normas técnicas; etc.).

g) Como a informação e a comunicação ocorre? O serviço está preparado para atender diferentes limitações?

h) Quando o usuário chega em busca do atendimento, procure imaginar todas as possibilidades que possam limitá-lo de alguma forma (visão, audição, movimentação, capacidade de pensamento, ação e comunicação etc.): como você acha que ele se sente? Você acredita que o serviço contempla o usuário considerando todas as suas características e capacidades?

i) Em consonância com a questão anterior, os profissionais são capacitados para atender a todos os tipos de pessoas (contemplando todas as suas características,

habilidades, limitações, capacidades e necessidades)? Como você se sente como colaborador da instituição para lidar com essas diferentes situações?

j) Existem no serviço sinalizações e materiais informativos acessíveis para o entendimento de pessoas com dificuldade de visão, por exemplo? O serviço possui informações em braille? Os materiais informativos possuem letras grandes e com linguagem simples? Para pessoas com perda de capacidade de audição, existe a presença de intérpretes no serviço? Para pessoas com alguma deficiência mental ou cognitiva, o espaço e seus profissionais estão preparados? Como funcionam essas questões para pessoas com outras deficiências ou com mobilidade reduzida? (pensemos em idosos, mulheres grávidas, cadeirantes, pessoas obesas, pessoas que dependam de muletas – entre tantas outras condições, momentâneas ou não, que podem ser limitantes em determinados contextos).

k) Imagine as características de pacientes com câncer e todas as capacidades perdidas nesse processo, você imagina que existam pontos do serviço ou etapas da jornada nas quais o usuário possa ficar excluído da utilização? Possa ter dificuldades de acesso? Qual(is)?

**Obs. 1: utilizar exemplos das percepções das informações coletadas nas observações não participantes para instigar a discussão.**

**Obs. 2: considerando que é um roteiro semiestruturado, a ordem da realização das perguntas mudou, além de que o direcionamento da conversa foi definido no momento da entrevista, conforme os assuntos.**

## **APÊNDICE D – ROTEIRO DA ENTREVISTA EM PROFUNDIDADE COM USUÁRIOS DO SERVIÇO E FAMILIARES/ACOMPANHANTES**

Objetivo: Verificar a percepção dos usuários e familiares/acompanhantes sobre o serviço de oncologia, como forma de entender sua jornada no serviço, experiência, dificuldades enfrentadas, e barreiras encontradas no que concerne à acessibilidade e à inclusão.

Participantes: usuário do serviço e familiares ou acompanhantes envolvidos.

Perfil do respondente: ( ) Usuário ( ) Familiar: \_\_\_\_\_ ( ) Acompanhante

Informações do usuário:

- Tempo de utilização do serviço: \_\_\_\_\_ (meses)
- Tipo de câncer que trata: \_\_\_\_\_
- Tratamentos realizados: \_\_\_\_\_
- Possui alguma outra doença crônica? Qual? \_\_\_\_\_
- Possui deficiência prévia à doença? Qual? \_\_\_\_\_
- Possui mobilidade reduzida? Especificar: \_\_\_\_\_
- Possui alguma limitação motora, cognitiva ou sensorial? Em relação a visão, audição, pensamento, destreza e alcance, e mobilidade (explicar cada uma se for necessário)? Qual? \_\_\_\_\_ Essa condição foi causada ou potencializada pelo câncer/tratamento? \_\_\_\_\_. Especifique.

**Questões gerais:**

- a) Comece falando um pouco sobre a sua história com o câncer até chegar nesse serviço.
- b) Quais são as suas redes de apoio?
- c) O que te motiva a continuar lutando contra a doença? No que você se apegar?
- d) Comente sobre como você percebe o funcionamento do serviço, desde a chegada até a saída? Qual o fluxo de atendimento que você segue no serviço?
- e) Como você se sente neste serviço de saúde?
- f) Como você chega ao serviço? De carro? Transporte público? Sozinho? Acompanhado?

**Questões específicas concernentes à acessibilidade e à inclusão:**

- a) Em termos de evidências físicas, como você se sente acessando o serviço? Você se localiza bem para chegar ao serviço desde a primeira vez que veio? Teve alguma dificuldade para encontrar o serviço alguma vez?
- b) Em termos de comunicação, você entende de maneira clara o que lhe é explicado?
- c) Você acha que os profissionais estão preparados para atendê-lo considerando todas as suas necessidades? Você acredita que eles estão preparados para atender a todos os pacientes que chegam no serviço?
- d) Você possui alguma limitação (relacionada a aspectos visão, audição, pensamento, destreza e alcance, e mobilidade) ao utilizar o serviço? Quer comentar a respeito? Em quais momentos você mais encontra dificuldades nesse sentido?
- f) De maneira geral, você encontra barreiras para acessar o serviço de alguma forma? Já se sentiu perdido em algum momento ou sentiu alguma dificuldade para acessar o serviço de forma plena?
- g) Você se sente incluído e sente que todas as suas necessidades são contempladas no serviço? Se não, por que? O que você acha que poderia ser diferente?
- h) Você se sente ou já se sentiu excluído de alguma etapa do serviço em algum momento? Já sentiu dificuldade de realizar alguma “tarefa” no serviço?
- i) Você enxerga pontos críticos e barreiras relativas à acessibilidade no serviço? Especifique.
- j) Com base no que conversamos, você tem sugestões de melhoria para o serviço? Como você acha que o serviço poderia ser melhor?
- k) O que você pensa sobre tecnologias auxiliando nos processos do serviço? (exemplo: um aplicativo ao invés de pastas e exames em papel). Comente um pouco sobre isso.
- l) Você tem algum outro ponto que gostaria de destacar?

**Obs. 1: utilizar exemplos das percepções das informações coletadas nas observações não participantes para instigar a discussão.**

**Obs. 2: considerando que é um roteiro semiestruturado, a ordem da realização das perguntas mudou, além de que o direcionamento da conversa foi definido no momento da entrevista, conforme os assuntos.**

**Obs. 3: quando as entrevistas foram realizadas com familiares/acompanhantes, as perguntas foram modificadas para a terceira pessoa do singular, se referindo às percepções desse familiar/acompanhante com o atendimento do paciente que acompanha.**

## APÊNDICE E – ROTEIRO E CRONOGRAMA DO WORKSHOP

Objetivo: contribuições complementares, a fim de entender a perspectiva de pessoas com deficiência sobre a jornada dos pacientes no serviço de oncologia. Além disso, buscou-se instigar a discussão para possíveis soluções para resolver as barreiras encontradas. A discussão sobre soluções em TICs também foi proporcionada.

Participantes: pacientes oncológicos (em tratamento ou sobreviventes), familiares/acompanhantes, profissionais de serviços de oncologia, pessoas com deficiência e especialistas/pesquisadores da área do design e deficiências.

Roteiro:

- Apresentação dos achados de pesquisa da primeira etapa, ressaltando os pontos críticos na análise da jornada do paciente no serviço;
- Cocriação com os participantes a fim de elaborar estratégias de melhoria aos gargalos identificados - nessa etapa haverá atenção aos pontos críticos
- Discussão sobre possíveis soluções às problemáticas.
- Discussão sobre TICs para resolver problemáticas do contexto e de acordo com as necessidades de cada usuário.

Cronograma:

<b>Etapa</b>	<b>Atividades</b>
Inspiração	<p>Apresentação dos achados da pesquisa e das barreiras identificadas no serviço, apresentação da jornada do usuário e dos pontos críticos relativos à acessibilidade e inclusão</p> <p>Apresentação das teorias do design que embasaram a pesquisa</p> <p><i>Brainstorming</i></p> <p>Geração de <i>insights</i></p>
Síntese	<p>Divisão dos participantes em grupos</p> <p>Trocas iniciais entre os grupos sobre os assuntos explanados</p>

	Identificação de problemas comuns Geração de ideias sobre problemas mais individuais em cada grupo
Ideação e experimentação	<i>Post-its</i> , canetas coloridas distribuídas nos grupos e desenhos da jornada e modelos da literatura distribuídos nos grupos Cocriação de soluções entre os participantes de cada grupo
Implementação	Apresentação das ideias de cada grupo para o grande grupo Ideias de soluções discutidas e escritas em um quadro Definição de prioridades e soluções

## ANEXO A – COMPROVANTE DE ACEITE DO COMITÊ DE ÉTICA EM PESQUISA DA UFCSPA

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### PARECER CONSUBSTANCIADO DO CEP

#### DADOS DO PROJETO DE PESQUISA

**Título da Pesquisa:** Potencialidades do Design na Experiência do Usuário em Serviços de Saúde

**Pesquisador:** Cláudia de Souza Libânio

**Área Temática:**

**Versão:** 1

**CAAE:** 55467222.5.0000.5345

**Instituição Proponente:** Universidade Federal de Ciências da Saúde de Porto Alegre

**Patrocinador Principal:** Financiamento Próprio

#### DADOS DO PARECER

**Número do Parecer:** 5.236.418

#### Apresentação do Projeto:

As informações elencadas neste campo foram retiradas do arquivo Informações Básicas da Pesquisa (PB\_INFORMAÇÕES\_BÁSICAS\_DO\_PROJETO\_1890268.pdf de 01/02/2022). Os serviços de saúde têm se tornado cada vez mais complexos. O aumento da incidência de doenças crônicas não transmissíveis, como o câncer, que representam as principais causas de adoecimento e mortes no mundo representa um dos desafios aos serviços de saúde. Nesse contexto, observam-se alguns gargalos nos serviços de saúde, que tomam o acesso inadequado, afetando a jornada do usuário no serviço e, conseqüentemente, sua experiência. Tendo em vista os desafios enfrentados pela área da saúde e o impacto sobre a jornada do paciente, verifica-se que o design pode contribuir, no sentido de oferecer valor e benefícios para o campo de análise. Com a compreensão de que o design pode ser utilizado para proporcionar soluções e melhorias no que concerne à experiência do usuário ao longo da jornada do paciente nos serviços de saúde, este estudo tem como objetivo verificar as potencialidades do design para contribuir com a experiência do usuário em serviços de saúde. Para isso, será realizada pesquisa exploratória de natureza aplicada. No que tange aos procedimentos técnicos, a pesquisa é bibliográfica, observacional e um estudo de campo, considerando que terá como base estudos já publicados, observação e coleta de dados em campo específico de estudo. Quanto ao método da abordagem do problema, a pesquisa é qualitativa e quantitativa. A coleta de dados será dividida em duas etapas: uma exploratória e uma descritiva. A

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etapa exploratória contemplará a realização de uma revisão sistemática da literatura (RSL) e entrevistas em profundidade semiestruturadas com profissionais que atuam em projetos de design e/ou tecnológicos na saúde. Essa fase tem como intuito explorar os conceitos centrais da abordagem teórica visando suportar, posteriormente, as pesquisas empíricas junto ao serviço escolhido. A etapa descritiva será dividida em dois momentos: 1) mapeamento da jornada do usuário - a ser realizada no Hospital Regina, em Novo Hamburgo/RS; e 2) workshop. O primeiro momento contará com quatro técnicas de coleta de dados, definidas em: a) observação não participante, b) entrevistas em profundidade com profissionais envolvidos no serviço escolhido, c) entrevistas em profundidade com o usuário e familiares/acompanhantes e, d) survey com usuários e familiares/acompanhantes. O segundo momento contará com o desenvolvimento do workshop. A combinação das técnicas indicadas nos dois momentos têm como intuito principal compreender a jornada do paciente e os pontos críticos do serviço de saúde, a fim de gerar oportunidades de melhoria. Quanto à análise dos dados qualitativos gerados, será realizada análise de conteúdo, visando apreciar conjuntamente os dados obtidos nas diferentes técnicas durante o processo metodológico. Os dados quantitativos serão analisados estatisticamente utilizando o software estatístico SPSS, visando apresentar análises descritivas.

**Objetivo da Pesquisa:**

**Objetivo Primário:**

Verificar as potencialidades do design para contribuir com a experiência do usuário em serviços de saúde.

**Objetivo Secundário:**

- Identificar as principais abordagens no campo do design de serviço que contribuem para a melhor experiência do usuário em saúde;- Mapear um serviço de saúde visando compreender a jornada do usuário;
- Mensurar a experiência do usuário no serviço de saúde, considerando os diferentes aspectos e momentos de interação;- Identificar pontos críticos da jornada do paciente concernentes com o design baseado em experiência;- Identificar pontos críticos da jornada do paciente concernentes com o design Inclusivo;- Diagnosticar oportunidades para o projeto de design de serviços.

**Avaliação dos Riscos e Benefícios:**

**Riscos:**

- Confidencialidade e privacidade em relação às informações expostas e à identificação do

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participante;- Privacidade de dados Institucionais: pode haver, por parte da Instituição incluída neste estudo, receio em relação a privacidade dos dados Institucionais de pacientes;

**Benefícios:**

Para o participante: oportunidade de contribuir com o entendimento da estruturação do serviço, pontos de contato de interação do usuário durante sua jornada no serviço, pontos críticos e de melhoria nos diversos pontos de contato etc. Sua participação poderá gerar melhorias no próprio serviço em que utiliza, seja como paciente, familiar/acompanhante ou profissional; oportunidade de cocriar ideias para a melhoria do serviço de saúde; e

oportunidade de compartilhar seu conhecimento na área e realizar trocas (principalmente para os profissionais externos ao serviço). Para a academia: pesquisas com foco na experiência do usuário em saúde contribuindo para a literatura da área; e maior inserção da pesquisa em design em saúde no Brasil. Para a sociedade: o entendimento das potencialidades do design para a melhoria de aspectos da experiência do usuário em

saúde pode auxiliar na melhoria da prestação de serviços em saúde no Brasil, o que pode refletir melhor acesso para a sociedade como um todo.

**Comentários e Considerações sobre a Pesquisa:**

Conforme Informações Básicas do Projeto na Plataforma Brasil, trata-se de uma pesquisa aplicada e exploratória, é uma pesquisa bibliográfica, observacional e um estudo de campo, considerando que terá como base estudos já publicados, observação e coleta de dados em campo específico de estudo. Quanto ao método da abordagem do problema, a pesquisa é qualitativa e quantitativa. A pesquisa tem início previsto para o 1º

semestre de 2022 e encerramento no 2º semestre de 2023.

**Considerações sobre os Termos de apresentação obrigatória:**

Termos obrigatórios apresentados de forma adequada.

**Recomendações:**

Iniciar coleta de dados somente após a aprovação do projeto junto ao CEP. Vide campo "Conclusões ou Pendências e Lista de Inadequações".

**Conclusões ou Pendências e Lista de Inadequações:**

O projeto está adequado para ser desenvolvido, tendo seu término previsto para 12/2023.

Ressalta-se que cabe ao pesquisador responsável encaminhar os relatórios parciais e final da pesquisa, por meio da Plataforma Brasil, via notificação do tipo "relatório" para que sejam devidamente apreciadas no CEP, conforme Norma Operacional CNS nº 001/12, Item XI.2.d.

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**Considerações Finais a critério do CEP:**

De acordo com o parecer do Relator.

Este parecer foi elaborado baseado nos documentos abaixo relacionados:

Tipo Documento	Arquivo	Postagem	Autor	Situação
Informações Básicas do Projeto	PB_INFORMAÇÕES_BÁSICAS_DO_PROJETO_1890268.pdf	01/02/2022 09:46:28		Acelto
Declaração de concordância	TERMO_ANUENCIA_Hospital_RegIna.pdf	01/02/2022 09:44:27	Emanuele König	Acelto
Solicitação Assinada pelo Pesquisador Responsável	TERMO_COMPROMISSO_RELATORIOS.pdf	01/02/2022 09:43:11	Emanuele König	Acelto
Outros	TCUD.pdf	01/02/2022 09:42:20	Emanuele König	Acelto
TCLE / Termos de Assentimento / Justificativa de Ausência	TCLE_USUARIOS_FAMILIARES.pdf	01/02/2022 09:41:32	Emanuele König	Acelto
TCLE / Termos de Assentimento / Justificativa de Ausência	TCLE_PROFSSIONAIS_SERVICO.pdf	01/02/2022 09:41:14	Emanuele König	Acelto
TCLE / Termos de Assentimento / Justificativa de Ausência	TCLE_PROFSSIONAIS_EXTERNOS.pdf	01/02/2022 09:39:38	Emanuele König	Acelto
Projeto Detalhado / Brochura Investigador	PROJETO_CEP.docx	01/02/2022 09:39:14	Emanuele König	Acelto
Folha de Rosto	FOLHA_DE_ROSTO.pdf	01/02/2022 09:38:38	Emanuele König	Acelto

**Situação do Parecer:**

Aprovado

**Necessita Apreciação da CONEP:**

Não

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PORTO ALEGRE, 10 de Fevereiro de 2022

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Assinado por:  
Fernanda Bordignon Nunes  
(Coordenador(a))

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