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LITERACIA EM SAÚDE DA PESSOA COM DIABETES E FAMÍLIA: EFETIVIDADE DE UMA INTERVENÇÃO PSICOEDUCATIVA DE ENFERMAGEM

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“Ensinar não é transferir conhecimento, mas criar as possibilidades para a sua própria produção ou a sua construção”

Paulo Freire

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RESUMO

Introdução: A diabetes mellitus é uma das principais condições crónicas a nível global, com uma prevalência crescente que representa um desafio significativo para a saúde pública, devido às suas potenciais complicações, ao impacto económico e às repercussões na qualidade de vida das pessoas diagnosticadas e famílias. A gestão da doença, especialmente em adultos, vai além da esfera individual, destacando-se o papel central da família no sucesso terapêutico e bem-estar global. Determinantes de saúde, como fatores socioeconómicos, culturais, ambientais, bem como a literacia em saúde, desempenham um papel essencial na promoção de comportamentos de prevenção e na autogestão efetiva da diabetes. No entanto, persistem lacunas no conhecimento sobre o impacto das dinâmicas familiares e da literacia em saúde na gestão da doença em adultos. Esta investigação, orientada pelo modelo de intervenções complexas da *Medical Research Council (MRC)* e pelos Modelos de Avaliação e Intervenção Familiar de *Calgary*, analisou como a participação ativa e intencional da pessoa com diabetes e da sua família, aliada à promoção da sua literacia em saúde, pode contribuir para melhores resultados em saúde e para a melhoria da qualidade de vida da pessoa diagnosticada e da sua família.

Metodologia: Este projeto de investigação teve início com uma análise aprofundada da literatura sobre a prevalência e complicações da diabetes, o impacto da literacia em saúde e o papel da família na autogestão da diabetes, assim como a efetividade das intervenções psicoeducativas e dos instrumentos de avaliação familiar. Para consolidar a base teórica e metodológica, forma conduzidas duas revisões sistemáticas: uma revisão das características psicométricas de instrumentos de avaliação familiar no adulto com diabetes, seguindo a metodologia da JBI e os critérios da COSMIN; e uma revisão *umbrella*, alinhada com a JBI, que sintetizou a evidência sobre a efetividade de programas de intervenção familiares no contexto do adulto com diabetes, abrangendo publicações entre 2013 e 2024.

Para aprofundar a compreensão das necessidades dos familiares, foi realizado um estudo em duas fases metodológicas: uma *scoping review*, conduzida de acordo com as guidelines PRISMA e metodologia JBI, analisou estudos publicados entre 2017 e 2023; e grupo focal, envolvendo 10 participantes, cujo conteúdo foi analisado com base nos critérios COnsolidated Criteria for Reporting Qualitative Research (COREQ).

Adicionalmente, de acordo com a taxonomia COSMIN, realizou-se a adaptação cultural e validação do instrumento *Family and Friend Involvement in Adults' Diabetes* para a população portuguesa (FIAD-PT), através de um estudo metodológico que garantiu a sua adequação psicométrica.

Na fase final da investigação, foi desenvolvido o programa de intervenção psicoeducativo Juntos *com a Família + Capazes* e realizada a sua avaliação conceptual. A estrutura do programa foi construída com base nos dados recolhidos ao longo do projeto de investigação, sendo a sua validação conceptual realizada através de três grupos focais.

Resultados: A inclusão da família na gestão da diabetes em adultos demonstrou ser um fator essencial para a melhoraria da adesão terapêutica, da autogestão da doença e da qualidade de vida. A revisão sistemática identificou 31 instrumentos de avaliação familiar, destacando cinco de acordo com os critérios da COSMIN, entre os quais o FIAD. A revisão *umbrela*, que incluiu cinco revisões sistemáticas, com qualidade metodológica variando entre baixa e alta, confirmou a efetividade das intervenções familiares. No entanto, evidenciou lacunas na descrição detalhada dessas intervenções, bem como uma significativa heterogeneidade entre as mesmas, dificultando a replicação e a avaliação comparativa da sua efetividade.

O estudo focado nas necessidades da família da pessoa adulta com diabetes, a partir da análise dos estudos incluídos (n=8) e da análise de conteúdo do grupo focal, permitiu identificar cinco temas centrais: (i) comunicação e expressão emocional no contexto familiar, (ii) impacto da diabetes na família, (iii) conhecimento específico sobre a diabetes, (iv) influências socioculturais e ambientais na gestão da doença e (v) comunicação com os profissionais de saúde.

A validação do FIAD, realizada através de uma amostra de 220 adultos com diabetes, confirmou a robustez psicométrica do instrumento, destacando-se como uma ferramenta útil para avaliar o impacto do envolvimento familiar na gestão da diabetes em adultos de língua Portuguesa. Por fim, o programa de intervenção *Juntos com a Família + Capazes* demonstrou potencial para capacitar a díade adulto com diabetes-família, promovendo uma gestão autónoma e efetiva da doença. A validação conceptual do programa, conduzida através de grupos focais com profissionais e pessoas com diabetes e suas famílias (n=19), permitiu ajustar a estrutura, os conteúdos e as estratégias metodológicas, garantindo a sua aplicabilidade e relevância nos diferentes contextos de implementação.

Conclusão: Esta investigação sublinha a importância de uma abordagem holística e centrada na família na gestão da diabetes, evidenciando o impacto positivo do envolvimento familiar na adesão terapêutica e na qualidade de vida. A promoção da literacia em saúde, aliada ao uso do FIAD-PT, permite avaliar e orientar intervenções mais adaptadas às necessidades e dinâmicas familiares, facilitando a autogestão da doença.

O programa de intervenção *Juntos com a Família + Capazes* adota uma abordagem flexível e adaptável, considerando fatores sociais, culturais e emocionais que influenciam a gestão da diabetes. e da sua família, integrando contextos sociais, culturais e emocionais. Ao integrar a família como elemento essencial no processo de cuidado, o programa tem o potencial de melhorar os resultados em saúde e fortalecer o suporte familiar.

A sua implementação em contextos clínicos poderá contribuir para a redução de complicações associadas à doença e otimizar recursos em saúde, reforçando a necessidade de estratégias que valorizem a participação ativa das famílias na gestão da diabetes.

Palavras-chave: Enfermagem em Saúde Comunitária, Programa, Literacia em Saúde; Família, Doença crónica, Diabetes, Adultos

Abstract

Introduction: Diabetes mellitus is one of the most prevalent chronic conditions globally, with an increasing incidence that poses a significant challenge to public health due to its potential complications, economic burden, and impact on the quality of life of diagnosed individuals and their families. Managing the disease, particularly in adults, extends beyond the individual sphere, highlighting the crucial role of the family in therapeutic success and overall well-being. Health determinants, including socioeconomic, cultural, and environmental factors, as well as health literacy, play a fundamental role in promoting preventive behaviors and the effective self-management of diabetes. However, gaps remain in understanding the impact of family dynamics and health literacy in adult diabetes management.

This research, guided by the Medical Research Council (MRC) framework for complex interventions and the Calgary Family Assessment and Intervention Models, examined how the active and intentional participation of individuals with diabetes and their families, combined with the promotion of their health literacy, can contribute to improved health outcomes and enhanced quality of life for both the diagnosed person and their family.

Methodology: This study began with an in-depth analysis of the literature on the prevalence and complications of diabetes, the impact of health literacy, the role of the family in diabetes self-management, and the effectiveness of psychoeducational interventions and family assessment tools. To consolidate the theoretical and methodological foundation, two systematic reviews were conducted: a review of the psychometric properties of family assessment instruments for adults with diabetes, following JBI methodology and COSMIN criteria, and an umbrella review, aligned with JBI guidelines, synthesizing evidence on the effectiveness of family intervention programs for adults with diabetes, covering publications from 2013 to 2024.

To further explore family needs, a two-phase methodological study was conducted: a scoping review, following PRISMA guidelines and JBI methodology, analyzed studies published between 2017 and 2023; and a focus group study, involving 10 participants, with content analysis guided by the Consolidated Criteria for Reporting Qualitative Research (COREQ).

Additionally, in line with COSMIN taxonomy, the Family and Friend Involvement in Adults' Diabetes (FIAD) instrument was culturally adapted and validated for the Portuguese population (FIAD-PT) through a methodological study, ensuring its psychometric robustness.

In the final phase of the research, the psychoeducational intervention program *Juntos com a Família + Capazes* was developed and conceptually validated. The program structure was based on data collected throughout the project, and its conceptual validation was carried out through three focus groups (n=19).

Results: Family involvement in adult diabetes management was shown to be essential for improving treatment adherence, disease self-management, and overall quality of life. The systematic review identified 31 family assessment instruments, with five meeting COSMIN criteria, including FIAD. The umbrella review, which included five systematic reviews of varying methodological quality (ranging from low to high), confirmed the effectiveness of family-centered interventions. However, it also highlighted gaps in their detailed descriptions and significant heterogeneity among them, making replication and comparative evaluation of their effectiveness challenging.

The study focusing on the needs of the families of adults with diabetes, based on the analysis of included studies (n=8) and the content analysis of the focus groups, identified five key themes: (i) communication and emotional expression within the family, (ii) the impact of diabetes on the family, (iii) diabetes-specific knowledge, (iv) sociocultural and environmental influences on disease management, and (v) communication with healthcare professionals.

The validation of FIAD, conducted with a sample of 220 adults with diabetes, confirmed the instrument's psychometric robustness, highlighting it as a valuable tool for assessing the impact of family involvement in diabetes management among Portuguese-speaking adults. Lastly, the intervention program Juntos com a Família + Capazes demonstrated significant potential to empower the adult-family dyad, promoting autonomous and effective disease management. The program's conceptual validation, conducted through focus groups with healthcare professionals, individuals with diabetes, and their families, enabled adjustments to its structure, content, and methodological strategies, ensuring its applicability and relevance across different implementation settings.

Conclusion: This study underscores the importance of a holistic, family-centered approach to diabetes management, highlighting the positive impact of family involvement on treatment adherence and quality of life. The promotion of health literacy, combined with the use of the FIAD-PT, facilitates the evaluation and implementation of interventions that are better tailored to the needs and dynamics of families, thereby enhancing disease self-management.

The *Juntos com a Família + Capazes* intervention program adopts a flexible and adaptable approach, considering social, cultural, and emotional factors that influence diabetes management. By integrating the family as a central component in the care process, the program has the potential to improve health outcomes and strengthen family support.

Its implementation in clinical settings may contribute to reducing diabetes-related complications and optimizing healthcare resources, reinforcing the need for strategies that actively engage families in diabetes management

Keywords: Community Health Nursing, Program, Health Literacy, Family, Chronic Disease, Diabetes, Adults

LISTA DE ABREVIATURAS, SIGLAS E ACRÓNIMOS

AVC	Acidente Vascular Cerebral
CFAM	Modelo de Avaliação Familiar de *Calgary*
CFIM	Modelo de Intervenção Familiar de *Calgary*
COREQ	COnsolidated Criteria for Reporting Qualitative Research
COSMIN	COnsensus-based Standards for the selection of health Measurement INstruments
DCV	Doença cardiovascular
DES-SF	Escala de Capacidade de Controlo da Diabetes - Versão Breve
DKT	Escala de Conhecimentos da Diabetes
DM	Diabetes Mellitus
DNT	Doenças não transmissíveis
EAM	Enfarte Agudo do Miocárdio
EQ-5D- 5L	Questionário de Avaliação de Ganhos em Saúde
FIAD	*Family And Friend Involvement in Adults' Diabetes*
HbA1c	Hemoglobina glicada A1c
HTA	Hipertensão Arterial
JBI	Joanna Briggs Institute
LS	Literacia em Saúde
ODS	Objetivos de Desenvolvimento Sustentável
OE	Ordem dos Enfermeiros
OECD	Organização para a Cooperação e Desenvolvimento Econômico
OMS	Organização Mundial de Saúde
PQCE	Padrões de Qualidade dos Cuidados de Enfermagem
RD	Retinopatia diabética
SPSS	Software Statistical Package for the Social Sciences
UCC	Unidade de Cuidados na Comunidade
UCSP	Unidade de Cuidados de Saúde Personalizados
USF	Unidade de Saúde Familiar

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DIVULGAÇÃO CIENTÍFICA REALIZADA NO ÂMBITO DA TESE

Artigos Científicos:

Soares, V. L., Sequeira, C., Morais, M. C. S., & Barbieri-Figueiredo, M. D. C. (2025). *Integrating Literature and Family Insights: Exploring the Needs of Families Supporting Adults with Diabetes*. *Frontiers in Public Health*, 12. https://doi.org/10.3389/fpubh.2024.1473723

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Capítulos de Livro:

Morais, C., **Soares, L**., & Barbieri-Figueiredo, M. C. (2021). *Promoção da literacia de pessoas com diabetes e famílias: um desafio à enfermagem familiar*. In Euromédice (Ed.), *Literacia em Saúde e Autocuidados: Evidências que projetam a prática Clínica* (pp. 133-143).

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Soares, V., Barbieri-Figueiredo, M. C., Sequeira, C., Morais, M. C., & Ferreira, P. L. (2024, 15 de julho). *Enhancing Diabetes Management: The Role of Family Health Literacy and Valid Assessment Tools*. [Apresentação em seminário].

Soares, V., Barbieri-Figueiredo, M. C., Sequeira, C., Morais, M. C., & Ferreira, P. L. (2024, 2 de julho). *Envolvimento da família e amigos na gestão da diabetes em adultos (FIAD-PT)*. [Apresentação em webinar]. Grupo de Estudos de Enfermagem em Diabetes (GEED - SPD), Sociedade Portuguesa de Diabetologia.

Comunicações em Conferências:

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INTRODUÇÃO

A Diabetes Mellitus (DM) constitui uma emergência global de saúde pública, sendo responsável por um elevado número de mortes prematuras, incapacidade e encargos económicos avultados para os sistemas de saúde (International Diabetes Federation, 2021). Apesar de integrar programas prioritários de saúde e estar presente nas agendas internacionais, as suas taxas de incidência e prevalência demonstram um aumento consistente e contínuo (International Diabetes Federation, 2021). Estima-se que, em 2045, cerca de 738 milhões de adultos viverão com DM, sendo 90% dos casos relacionados com DM tipo 2 (International Diabetes Federation, 2021). Em Portugal, a prevalência da doença atinge cerca de 13,6% da população adulta (20-79 anos), com maior incidência nos grupos etários mais velhos (60-79 anos) e nos homens (Observatório Nacional da Diabetes, 2019).

A natureza multifatorial da diabetes, que inclui determinantes socioeconómicos, demográficos, ambientais e genéticos, exige uma abordagem holística e integrada, envolvendo profissionais de saúde, a pessoa diagnosticada, a sua família e os parceiros comunitários que constituem a rede social dos diferentes contextos (American Diabetes Association, 2023; International Diabetes Federation, 2021).

A diabetes é uma doença progressiva, que clinicamente mal controlada tem o potencial de afetar negativamente diversos sistemas do corpo humano (American Diabetes Association, 2023; International Diabetes Federation, 2021). A gestão eficiente da doença, centrada no controlo glicémico, depende da autogestão e do conhecimento específico sobre a doença, o que engloba alterações nos estilos de vida e adesão ao regime terapêutico medicamentoso (American Diabetes Association, 2023; Protheroe et al., 2017).

As *guidelines* internacionais para os cuidados com a diabetes destacam a importância de garantir que todas as pessoas diagnosticadas com a doença tenham acesso a sessões educativas (American Diabetes Association, 2023). Estas iniciativas não se limitam a aumentar o conhecimento específico sobre a doença, mas visam também desenvolver competências essenciais para a autogestão eficiente (American Diabetes Association, 2023). Ao afastarem-se de uma abordagem exclusivamente biomédica, estas intervenções adotam uma perspetiva holística da pessoa, que, segundo a evidência, está associada à redução de comportamentos de risco, hábitos de vida não saudáveis e hospitalizações (Asmat et al., 2022; World Health Organization, 2013). Contudo, estratégias centradas apenas na pessoa diagnosticada têm revelado limitações na resposta aos múltiplos desafios impostos pela DM

Neste contexto, a literacia em saúde assume um papel central, sendo reconhecida ao longo dos anos como um forte indicador do estado de saúde das populações (World Health Organization, 2013). Este conceito ultrapassa a mera aquisição de conhecimentos, relacionando-se diretamente com a capacidade de interpretar, avaliar e aplicar criticamente a informação, promovendo decisões informadas e fundamentadas sobre a condição de saúde. Na diabetes, a promoção da literacia em saúde transcende o acesso a informações específicas sobre a doença, seja através de fontes online, panfletos ou orientações dos diferentes profissionais de saúde (World Health Organization, 1986, 2013, 2021). Implica capacitar a pessoa a expressar as suas necessidades reais, de forma clara e fundamentada, assim como a exercer um juízo crítico sobre a informação recebida e os recursos de saúde disponíveis (World Health Organization, 1986, 2013, 2021). Este nível de literacia é essencial para que a pessoa alcance o seu potencial máximo de saúde, promovendo a transição de uma perspetiva individual para um envolvimento mais ativo no controlo dos determinantes de saúde, tanto no contexto pessoal quanto comunitário (Sørensen, 2022)

O diagnóstico de diabetes, porém, não afeta apenas a pessoa diagnosticada, mas também os contextos sociais, familiares, profissionais e comunitários em que esta está inserida (McEwen et al., 2019). A gestão diária da doença crónica, designadamente da DM dependem, em grande medida, do contexto familiar**,** ampliando os desafios impostos pela doença a toda a estrutura familiar (Hanson, 2005; Shajani & Snell, 2019). Embora a família desempenhe um papel central na gestão da diabetes, a evidencia destaca níveis frequentemente baixos de literacia em saúde e de conhecimento específico sobre a doença entre adultos diagnosticados e os seus familiares (Nugent et al., 2023; Oliveira & Morais, 2016; Panagiotidis et al., 2024). Simultaneamente, a família constitui uma fonte primária de suporte e tem um impacto determinante na forma como a pessoa diagnosticada enfrenta os desafios da doença (Hanson, 2005; Shajani & Snell, 2019).

Num contexto internacional, onde a prevenção e o controlo da diabetes são prioridades, o suporte social, particularmente o envolvimento familiar, tem sido amplamente avaliado (Lee, 2018; McEwen et al., 2019; Pamungkas et al., 2017; Soares et al., 2024). A evidência demonstra que este envolvimento está positivamente associado à melhoria e manutenção dos indicadores clínicos, reforçando a importância do papel da família na adesão ao regime terapêutico e na sustentabilidade das mudanças comportamentais necessárias à gestão efetiva da doença (Lee, 2018; McEwen et al., 2019; Pamungkas et al., 2017).

Perante este enquadramento, este projeto de investigação foi orientado pela seguinte pergunta central: **Quais os ganhos em saúde para a pessoa com DM e sua família decorrentes do envolvimento ativo e intencional da família na gestão da doença?** Para dar resposta a esta questão, foram desenvolvidos estudos que exploraram de forma aprofundada os potenciais benefícios do empoderamento da pessoa diagnosticada e da sua família, abrangendo não apenas os resultados clínicos, mas também os impactos emocionais, sociais e funcionais na qualidade de vida de todos os envolvidos.

Este empoderamento assenta no aumento dos níveis de literacia em saúde, capacitando os participantes a desenvolverem maior autonomia e competências de autogestão, essenciais para uma gestão efetiva da doença, em parceria ativa com os profissionais de saúde. O projeto de investigação adota uma abordagem sistémica e holística no cuidado ao adulto com diabetes e sua família, considerando as dinâmicas familiares, as especificidades individuais e os contextos socioeconómicos e culturais envolvidos (Shajani & Snell, 2019).

A investigação foi estruturada em quatro estudos complementares, tendo por base o Modelo de Intervenções Complexas do Medical Research Council (MRC), resultando no desenvolvimento do programa de intervenção psicoeducativa de enfermagem denominado *Juntos com a Família + Capazes* (Bleijenberg et al., 2018; Craig et al., 2008; Richards & Hallberg, 2015).

A estrutura da tese segue a lógica metodológica do Modelo de Intervenções Complexas do MRC, sendo cada capítulo correspondente a uma das suas fases. A organização sequencial e estruturada dos capítulos reflete as etapas delineadas pelo modelo, sistematizando as atividades desenvolvidas em cada fase. Desta forma, garante-se uma apresentação clara e coerente do percurso metodológico. As fases descritas incluem: I) definição e identificação do problema em estudo; II) identificação de uma teoria; III) identificação da evidência e análise da prática corrente e contexto atual; IV) determinar necessidades e (V) modelação do processo e dos resultados esperados. Embora estas fases sejam conceptualizadas de forma clara e bem delimitada no modelo, a sua aplicação na prática é interativa e interligada, permitindo revisões e adaptações contínuas ao longo do processo (Bleijenberg et al., 2018; Craig et al., 2008; Richards & Hallberg, 2015)

Adotaram-se abordagens metodológicas mistas**,** combinando métodos quantitativos e qualitativos em diferentes etapas, de acordo com os objetivos definidos em cada fase. Esta abordagem permitiu integrar dados diversificados, enriquecendo a análise e garantindo uma

compreensão mais abrangente da área em estudo, assegurando a relevância e eficácia do programa (Bleijenberg et al., 2018; Craig et al., 2008; Richards & Hallberg, 2015).

Assim, no Capítulo I – Definição e Identificação do problema foi incluída uma descrição detalhada sobre a diabetes, assim como as necessidades e lacunas existentes na gestão da diabetes, com ênfase no impacto das dinâmicas familiares. Este capítulo está organizado em quatro grandes temas: (i) Diabetes: prevalência, complicações e relevância em saúde pública, abordando a magnitude e o impacto desta condição; (ii) Literacia em saúde do adulto com diabetes, explorando a sua importância na autogestão da doença; (iii) O papel da família na gestão da diabetes, destacando a influência das dinâmicas familiares nos resultados em saúde; e (iv) Intervenções psicoeducativas de enfermagem, analisando estratégias que promovem a capacitação e o bem-estar do adulto com diabetes e da sua família.

O Capítulo II – Identificação de uma teoria, descreve os Modelos de Avaliação e Intervenção Familiar de *Calgary* (CFAIM) que constituíram a base teórica deste projeto de investigação. Estes modelos proporcionam um enquadramento conceptual para compreender e intervir nas dinâmicas familiares, assim como orientar as intervenções que promovam o bem-estar e a capacitação da pessoa com diabetes e da sua família, abordando de forma integrada as suas necessidades no contexto da gestão da doença.

O Capítulo III – Identificação da evidência e análise da prática corrente e contexto atual complementam a fundamentação teórica das fases anteriores e inclui dois artigos que fornecem uma base empírica e prática para este projeto de investigação. O primeiro artigo consiste numa revisão sistemática de propriedades psicométricas, que identificou instrumentos de avaliação familiar utilizados no contexto do adulto com diabetes, essenciais para garantir a avaliação da eficácia das intervenções. O segundo artigo apresenta uma revisão umbrela que analisou a efetividade das intervenções focadas na família do adulto com diabetes, sistematizando os resultados de cinco revisões sistemáticas previamente publicadas. Esta revisão fornece uma visão abrangente das estratégias e componentes que se revelaram mais efetivas na melhoria dos resultados em saúde e na capacitação das famílias, evidenciando as melhores práticas e lacunas a serem abordadas.

O Capítulo IV – Determinar necessidades focou-se em explorar as perspetivas sobre a gestão da diabetes no adulto e em identificar lacunas relacionadas com o envolvimento familiar nos cuidados. Para esta fase, foi conduzido um estudo metodológico, descrito num artigo científico publicado, que integrou duas metodologias complementares: uma *scoping review* destinada a sintetizar a evidência existente sobre as necessidades e o papel da família na gestão da

diabetes; e grupos focais, envolvendo adultos com diabetes e os seus familiares, que permitiram uma análise aprofundada das necessidades emocionais, sociais e práticas associadas à gestão da doença (Soares et al., 2025). Adicionalmente, foram conduzidas reuniões com profissionais de saúde, particularmente enfermeiros, com o objetivo de explorar as perspetivas sobre a gestão da diabetes no adulto e identificar lacunas relacionadas com o envolvimento familiar nos cuidados. Estas abordagens conjuntas permitiram identificar lacunas relevantes e enriquecer o desenvolvimento subsequente do programa de intervenção, assegurando a sua pertinência e alinhamento com as necessidades identificadas.

O Capítulo V – Modelação do processo e dos resultados esperados descreve as etapas finais do desenvolvimento do programa *Juntos com a Família + Capazes*, incluindo o estudo de adaptação e validação do instrumento *Family and Friend Involvement in Adults' Diabetes* (FIAD) para a população portuguesa. Este instrumento, selecionado pela sua pertinência e robustez psicométrica robustas na fase anterior, foi adaptado para avaliar de forma precisa o envolvimento familiar na gestão da diabetes no contexto nacional. Adicionalmente, o FIAD-PT será um dos instrumentos utilizados para avaliar a efetividade do programa desenvolvido ao longo deste projeto de investigação.

Esta fase teve como objetivo testar e refinar a intervenção, assegurando a sua eficácia e adaptabilidade às necessidades da população-alvo (Bleijenberg et al., 2018).

O design do programa de intervenção integrou os contributos das fases anteriores, sendo o seu desenvolvimento descrito num estudo de natureza qualitativa. A validação conceptual do programa de foi conduzida através de uma abordagem qualitativa, recorrendo à metodologia de grupos focais, permitindo a recolha de perspetivas de profissionais de saúde, adultos diagnosticados com diabetes e seus familiares. Adicionalmente, foi elaborado um guia orientador do programa, destinado a apoiar os profissionais de saúde responsáveis pela sua implementação, assegurando que as estratégias propostas sejam aplicadas de forma estruturada e adaptada às necessidades dos participantes.

As diferentes fases do Modelo MRC, os objetivos, os métodos e os resultados/publicações decorrentes deste projeto de investigação estão detalhados na Tabela 1, permitindo uma visão integrada do percurso metodológico seguido ao longo da tese.

A avaliação da efetividade, nesta tese, centrou-se na sua validação conceptual, uma etapa fundamental no desenvolvimento de intervenções, que, ao contrário da avaliação baseada nos resultados esperados, permitiu integrar as necessidades identificadas pelos participantes e os contributos de uma equipa multidisciplinar, incluindo adultos com diabetes e seus familiares,

através de grupos focais, assegurando assim que o programa seja relevante, adaptável ao contexto e orientado para o empoderamento da díade – adulto com diabetes e sua família.

A validação conceptual possibilitou ajustes e aprimoramentos na estrutura do programa, criando condições para maximizar a sua efetividade, garantindo a aplicabilidade e o impacto em contextos reais. Desta forma, estão reunidas as condições que garantem a avaliação da efetividade desta intervenção, por meio da análise inicial e final das variáveis em estudo, nomeadamente as variáveis clínicas que incluem o Índice de Massa Corporal, a hemoglobina glicada, o perímetro abdominal, a pressão arterial mínima e máxima, o consumo de álcool medido (número de copos/ dia) e os hábitos tabágicos (número de cigarros/dia), bem como as variáveis comportamentais e psicossociais que incluem o consumo regular de uma dieta equilibrada e adaptada à gestão da diabetes, a prática de exercício físico regular (número de horas praticadas/ semana), o conhecimento específico sobre a diabetes, a qualidade de vida relacionada com a saúde, a autoeficácia da pessoa com diabetes e o funcionamento familiar.

No Capítulo VI – Discussão centra-se na análise e interpretação dos resultados obtidos ao longo da investigação, discutindo a sua relevância à luz da literatura existente. Este capítulo aborda as implicações destes resultados para a prática de enfermagem, a educação em saúde e as políticas de saúde, apontando caminhos para uma abordagem mais integrada e sustentável. Destaca-se, também, o contributo desta investigação para o enriquecimento do conhecimento disciplinar em Enfermagem, reconhecida como uma ciência humana centrada nos cuidados. A complexidade dos fenómenos que aborda e a exigência pela constante melhoria da qualidade dos cuidados prestados à pessoa, família e comunidade configuram desafios permanentes para os profissionais em diversos contextos. Assim, a investigação assume um papel estruturante, essencial à renovação e ampliação contínua do corpo de saberes da disciplina de Enfermagem.

A Conclusão apresenta uma síntese das principais conclusões da investigação, apresentando recomendações para a prática clínica e para futuros estudos.

Tabela 1. Relação entre as fases do Modelo MRC, objetivos, métodos e resultados/publicações do projeto de investigação

FASES MRC	OBJETIVO	MÉTODO	RESULTADOS/PUBLICAÇÕES
IDENTIFICAÇÃO DA EVIDÊNCIA / ANÁLISE DA PRÁTICA CORRENTE E CONTEXTO ATUAL	Identificar e avaliar as propriedades psicométricas dos instrumentos utilizados para avaliar o funcionamento familiar em adultos com diabetes.	Revisão Sistemática das Características Psicométricas	"*Diabetes Mellitus Family Assessment Instruments: A Systematic Review of Measurement Properties"* – Publicado no *International Journal of Environmental Research and Public Health* (2023)
	Identificar e sintetizar a evidência no âmbito das intervenções centradas na família com o adulto diagnosticado com diabetes	Revisão *Umbrela*	*"Effectiveness of family-focused interventions for adults with diabetes: an Umbrella Review"* – submetido para publicação
DETERMINAR NECESSIDADES	Explorar e compreender as necessidades e/ou perceções dos familiares de adultos com diabetes.	Estudo desenvolvido em duas fases: (1) scoping review; (2) grupos focais	***"****Integrating Literature and Family Experiences: A Study on the Needs of Families of Adults with Diabetes"*– Publicado no *Frontiers in Public Health* (2025)
	Explorar e compreender as necessidades expressas pelos profissionais de saúde	Reuniões Informais com os Profissionais	Programa *Juntos com a Família + Capazes* – Guia orientador para profissionais

	Adaptar e validar o instrumento de avaliação da família para a população portuguesa	Estudo de Adaptação cultural e Validação	*"Cultural Adaptation and Validation of the Family and Friend Involvement in Adults' Diabetes (FIAD) Scale for Portuguese Population"* – submetido para publicação
MODELAÇÃO DO PROCESSO E RESULTADOS ESPERADOS	Desenvolver e validar conceptualmente o programa de intervenção psicoeducativa de enfermagem	Estudo Qualitativo	*"Building a Family-Centered Intervention for Adults with Diabetes: Theoretical Foundations"*– submetido para publicação Conceptual Validation of a Family-Centered Diabetes Intervention: Insights from Multidisciplinary Focus Groups – submetido para publicação Programa *Juntos com a Família + Capazes* – Guia orientador para profissionais

CAPÍTULO I – DEFINIÇÃO E IDENTIFICAÇÃO DO PROBLEMA

1. DIABETES: PREVALÊNCIA, COMPLICAÇÕES E RELEVÂNCIA EM SAÚDE PÚBLICA

A Diabetes Mellitus (DM), reconhecida como uma das mais graves emergências de saúde a nível global, afeta atualmente cerca de 537 milhões de adultos, com idades entre os 20 e os 79 anos, em todo o mundo (International Diabetes Federation, 2021). As projeções indicam um aumento para 643 milhões em 2030 e 783 milhões em 2045, refletindo o a crescente urgência da sua inclusão como prioridade agendas políticas globais (International Diabetes Federation, 2021).

A diabetes é uma doença metabólica de longa duração caracterizada pelo aumento da glicose no sangue na ausência de tratamento, designada como hiperglicemia (World Health Organization, 2019a). A sua etiopatologia heterogénea inclui alterações na capacidade do corpo produzir insulina, na ação da insulina que produz, ou em ambos e também distúrbios no metabolismo dos hidratos de carbono, gorduras e proteínas (International Diabetes Federation, 2021; World Health Organization, 2019a).

Assintomática nos estádios iniciais ou apresentando sintomas pouco evidentes, a diabetes é uma doença silenciosa. Estima-se que cerca de 240 milhões de pessoas desconheçam a sua condição clínica, permanecendo por diagnosticar (International Diabetes Federation, 2021).

A variação no diagnóstico da diabetes entre países é frequentemente influenciada por diversos fatores, como a genética, as condições socioeconómicas, o desempenho dos sistemas de saúde locais e o nível de sensibilização do público e dos profissionais de saúde em relação à diabetes (OECD, 2023). Os dados indicam que há uma maior prevalência da diabetes nas zonas urbanas, nas pessoas mais velhas e nos homens (International Diabetes Federation, 2021). De acordo com a mesma fonte cerca de 87,5% dos casos de diabetes não diagnosticados encontram-se em países de baixo e médio rendimento, com aproximadamente 50,5% desses casos localizados em países de baixo rendimento.

Atualmente considerada uma emergência global de saúde, a diabetes exerce um impacto económico significativo sobre os indivíduos diagnosticados, as suas famílias, comunidades e os sistemas de saúde (Direção Geral da Saúde, 2017; Elsayed et al., 2024).O aumento da sua prevalência pode ser atribuído a rápidas mudanças culturais e sociais, a alterações nos padrões alimentares, ao envelhecimento da população, ao sedentarismo e a estilos de vida pouco saudáveis, bem como à crescente urbanização e a outros comportamentos não saudáveis (Sociedade Portuguesa de Diabetologia, 2023).

A hiperglicemia não diagnosticada ou não tratada pode originar complicações incapacitantes ou potencialmente fatais em vários órgãos (Loscalzo et al., 2023). As complicações da diabetes incluem a arteriosclerose e danos no coração, cérebro, olhos, rins, nervos e pele, dando origem a doenças cardiovasculares, doença renal crónica, perda de visão (retinopatia diabética), neuropatia e úlceras e infeções nos pés (Loscalzo et al., 2023). O tratamento e controlo das complicações decorrentes de uma gestão inadequada da diabetes exigem cuidados médicos contínuos, comprometem a qualidade de vida dos indivíduos diagnosticados, aumentam o absentismo laboral e podem resultar em morte prematura (International Diabetes Federation, 2021).

Globalmente, a diabetes é identificada como uma das principais causas de mortalidade. Em 2021, o seu tratamento e controlo representaram cerca de 11,5% das despesas globais em saúde (International Diabetes Federation, 2021). Em Portugal, embora se observe uma evolução positiva em alguns indicadores, como a redução significativa do número de anos potenciais de vida perdidos devido à diabetes (cerca de 34%), a taxa de prevalência da doença permanece elevada, situando-se em cerca de 14,1% (Sociedade Portuguesa de Diabetologia, 2023). Apesar da ligeira diminuição da representatividade da diabetes entre as causas de morte no país, esta doença foi responsável por cerca de 3,3% dos óbitos ocorridos em 2020. Importa também salientar o aumento documentado do número absoluto de óbitos registados, assim como da letalidade intra-hospitalar em internamentos onde a diabetes é o diagnóstico principal (Sociedade Portuguesa de Diabetologia, 2023).

Neste contexto, o forte impacto económico da diabetes na pessoa diagnosticada, família, comunidades, nos países e respetivos sistemas de saúde tem vindo a ser amplamente abordado (International Diabetes Federation, 2021, 2023). Os gastos globais em saúde devido à diabetes incluem os custos diretos, associados ao tratamento da doença e respetivas complicações e os custos indiretos que incluem a diminuição do capital humano e social impostos pelas faltas e incapacidade para o trabalho e em casos extremos a morte prematura (International Diabetes Federation, 2021, 2023).

Os custos diretos da diabetes incluem o acesso aos cuidados de saúde de forma regular aos diferentes níveis de cuidados, a realização regular de exames auxiliares de diagnóstico para controle e gestão da doença, assim como os episódios de internamento por situações de descompensação da diabetes. Nestes encontram-se também englobados os custos associados aos materiais específicos para o autocontrole da glicemia e administração da medicação prescrita, assim como dos fármacos. Os tratamentos associados às complicações

da diabetes podem incluir internamentos prolongados hemodiálise em caso de insuficiência renal crónica; tratamentos de fotocoagulação em caso de retinopatia diabética; cirurgias para amputação e em alguns casos a necessidade de uso de próteses (Loscalzo et al., 2023).

O aumento das despesas globais em saúde devido à diabetes tem sido amplamente documentado, passando de 232 mil milhões de dólares em 2007 para 966 mil milhões de dólares em 2021, referente a adultos entre os 20 e 79 anos. Este aumento representa cerca de 316% ao longo dos últimos 15 anos, estando previsto que a tendência de crescimento se manterá nos próximos anos (International Diabetes Federation, 2021). Portugal não foi uma exceção a esta tendência, com um aumento significativo dos encargos relacionados com medicamentos e dispositivos para tratamento e monitorização da diabetes, bem como custos associados aos internamentos (Ministério da Saúde, 2023b; Sociedade Portuguesa de Diabetologia, 2023).Os custos relacionados com a diabetes são elevados e difíceis de contabilizar na sua totalidade, uma vez que frequentemente não incluem os encargos com episódios de internamento de ambulatório, nem os custos dos internamentos das pessoas com diabetes com outro diagnóstico principal. Estas pessoas apresentam uma morbilidade mais elevada e internamentos mais prolongados em comparação às pessoas sem diabetes (Ministério da Saúde, 2023b; Sociedade Portuguesa de Diabetologia, 2023).

A melhoria da qualidade de vida das pessoas diagnosticadas e a redução da sobrecarga do tratamento da diabetes sobre os serviços de saúde só serão possíveis através da prestação de cuidados de saúde primários de elevada qualidade, do diagnóstico precoce e da gestão efetiva da diabetes, reconhecidos como elementos essenciais para prevenir diagnósticos tardios e complicações graves (International Diabetes Federation, 2021; Sociedade Portuguesa de Diabetologia, 2023).

1.1. Diagnóstico de Diabetes Mellitus

Os critérios clínicos de diagnóstico da DM têm sofrido alterações de acordo com a evolução do conhecimento científico.

Atualmente são considerados critérios de diagnostico da doença a hemoglobina glicada (HbA1c) com valor igual ou superior a 6,5%, a glicemia em jejum igual ou superior a 126 mg/dl e níveis de glicose no sangue superiores ou iguais a 200 mg/dl após duas horas da ingestão de 75g de glicose (American Diabetes Association, 2023).

Em Portugal, os critérios de diagnostico de DM adotados incluem: i) glicemia em jejum ≥ 126 mg/dl (ou ≥ 7,0 mol/l); sintomas clássicos de descompensação associados a uma glicemia

ocasional ≥ 200 mg/dl (ou ≥ 11,1 mmol/l); glicemia ≥ 200 mg/dl (ou ≥ 11,1 mmol/l) duas horas após a prova de tolerância à glicose oral (PTGO) com 75g de glicose; e HbA1c ≥ 6,5 % (Direção Geral da Saúde, 2011).

1.2. Tipos de Diabetes Mellitus

Embora a etiologia e a patogénese da diabetes sejam frequentemente descritas de forma simplificada como alterações na sensibilidade à insulina e na sua secreção, o complexo mecanismo subjacente às formas comuns de diabetes tem vindo a integrar conhecimentos sobre fatores genéticos, epigenéticos, proteómicos e metabólicos (World Health Organization, 2019a). Nesta tese serão abordadas de forma sucinta as duas formas mais comuns de diabetes: a diabetes tipo 1 e diabetes tipo 2.

- Diabetes tipo 1

A diabetes tipo 1 ocorre frequentemente na infância, no entanto, o seu início também pode ocorrer na idade adulta, sendo que 84% das pessoas que vivem com DM tipo 1 são adultas (World Health Organization, 2019). O surgimento deste tipo de diabetes é geralmente repentino, e o controle da doença e dos valores de glicemia, impõe a necessidade de administração de insulina injetável (World Health Organization, 2019a).

A incidência da diabetes tipo 1 tem aumentando na grande maioria dos países estudados, sendo a sua distribuição desigual em alguns países (International Diabetes Federation, 2021). Entre 70% e 90% das pessoas com diabetes tipo 1 apresentam, no momento do diagnóstico, um processo imunomediado, caracterizado pela presença de autoanticorpos contra as células β do pâncreas, resultando numa acentuada diminuição ou ausência de produção da insulina pelo pâncreas (World Health Organization, 2019a).

Homens e mulheres são igualmente afetados, com os dados a indicarem que o diagnóstico de diabetes tipo 1 está associado a uma redução da expectativa de vida da pessoa diagnosticada em aproximadamente 13 anos nos países de elevado rendimento (World Health Organization, 2019a). Segundo a mesma fonte este prognóstico é ainda pior nos países com acesso limitado à insulina

As causas da diabetes tipo 1 não são totalmente conhecidas, no entanto a reação autoimune que associada a esta condição é descrita na literatura como o resultado de uma combinação de fatores genéticos (maior suscetibilidade genética) e ambientais como o aumento da altura e de peso, o aumento da idade materna no parto, alguns aspetos da alimentação, bem como a exposição a certas infeções (Observatório Nacional da Diabetes, 2019; World Health

Organization, 2019). Os sintomas mais frequentes da diabetes tipo 1 incluem: sede anormal e secura de boca; micção frequente; cansaço/falta de energia; fome constante; perda de peso súbita; feridas de cura lenta; infeções recorrentes; visão turva (Observatório Nacional da Diabetes, 2019; World Health Organization, 2019b).

Embora viver com diabetes tipo 1 seja desafiante para a pessoa diagnosticada e para a família, é possível atrasar ou evitar as complicações associadas à doença e viver uma vida saudável através do tratamento diário com insulina injetável, da monitorização regular dos níveis de glicose e do acesso ao suporte social e aos profissionais de saúde (International Diabetes Federation, 2021).

- Diabetes tipo 2

A diabetes tipo 2 é a forma mais frequente de diabetes, representando cerca de 90% dos casos de a nível mundial (International Diabetes Federationt, 2019; World Health Organization, 2019a). A sua prevalência é mais elevada nos países de baixo e médio rendimento e está associada a rápidas mudanças culturais, económicas e sociais, ao envelhecimento da população mundial, à rápida e muitas vezes desordenada urbanização, e às suas consequências nos hábitos de vida e nos padrões de comportamento (alimentação pouco saudável, sedentarismo, aumento do peso/ obesidade) e ao aumento da exposição fetal à hiperglicemia durante o período de gravidez (International Diabetes Federationt, 2019; World Health Organization, 2019a).

Embora mais comum em adultos, a diabetes tipo 2 afeta um número crescente de crianças e adolescentes (International Diabetes Federationt, 2019; World Health Organization, 2019a).Os sintomas são semelhantes aos da diabetes tipo 1, no entanto não surgem de forma tão intensa, ou as pessoas permanecem assintomáticas durante muito tempo. A hiperglicemia subjacente à diabetes tipo 2 resulta da insulinopenia relativa (diminuição parcial da produção de insulina pelas células beta do pâncreas), com maior ou menor grau de insulinorresistência, isto é a resistência do organismo á ação da insulina (International Diabetes Federation, 2021).

A presença contínua, e muitas silenciosas, da hiperglicemia até ao momento do diagnóstico, decorrente frequentemente de exames de rotinas ou internamentos, pode conduzir ao desenvolvimento de complicações graves, tanto macrovasculares como microvasculares (International Diabetes Federation, 2021). Embora a maioria das pessoas diagnosticadas com este tipo de diabetes não necessite de tratamento com insulina para sobreviver, a maioria requer antidiabéticos orais como estratégia fundamental para reduzir a glicemia (International Diabetes Federation, 2021).

As complicações associadas ao início precoce da diabetes tipo 2 são um problema global de saúde, pela sua associação a taxas de mortalidade e morbilidade mais elevadas e enquanto fatores de risco para doenças cardiovasculares comparativamente á diabetes tipo 1.

Embora a etiologia específica da diabetes tipo 2 ainda não esteja completamente esclarecida, é provável que reflita uma combinação de diferentes mecanismos (World Health Organization, 2019). A sua gestão, com consequente diminuição das complicações, implica, para além da adesão ao regime terapêutico medicamentoso prescrito, a adoção de um estilo de vida saudável no qual se incluem alimentação equilibrada, prática de exercício físico regular, assim como a cessação dos hábitos tabágicos (International Diabetes Federationt, 2019; World Health Organization, 2019a).

1.3. Complicações Potenciais Associadas à Diabetes Mellitus

Independentemente da fisiopatologia, a diabetes é uma doença metabólica na qual a presença de níveis elevados de glicose é o fator primário desencadeador de complicações que afetam vários órgãos como o coração, olhos, rins e nervos periféricos (International Diabetes Federation, 2021; Loscalzo et al., 2023).

A patogénese das alterações fisiológicas e metabólicas decorrentes da hiperglicemia envolve mecanismos fisiológicos, biológicos e bioquímicos de grande complexidade, que afetam significativamente a qualidade de vida da pessoa com diabetes (International Diabetes Federation, 2021; Loscalzo et al., 2023). Quando diagnosticada tardiamente, esta hiperglicemia é responsável por um elevado número de mortes prematuras e incapacidades comprometendo a vida pessoal da pessoa diagnostica, da sua família e comunidade. Adicionalmente implica a diminuição do capital social e humano e avultados custos aos sistemas de saúde (International Diabetes Federation, 2021)

As complicações da diabetes podem ser agudas e crónicas. As complicações agudas mais frequentes são a hipoglicemia, a cetoacidose diabética, o estado de hiperglicemia hiperosmolar e o coma hiperglicémico hiperosmolar (International Diabetes Federation, 2021; Loscalzo et al., 2023). As complicações crónicas incluem a doença cardiovascular, a retinopatia, a nefropatia, a neuropatia e o pé diabético. A hiperglicemia não tratada encontra-se associada ao aumento do número de casos de cancro, alterações cognitivas e físicas (International Diabetes Federation, 2021; Loscalzo et al., 2023).

I. Doença cardiovascular: A doença cardiovascular (DCV) constitui uma preocupação significativa para as pessoas com diabetes que apresentam um risco

duas a três vezes superior de desenvolver DCV em comparação com pessoas sem esta patologia (International Diabetes Federation, 2021; Loscalzo et al., 2023). Este risco acrescido está associado à presença de hiperglicemia, que pode alterar a coagulação sanguínea, favorecendo a formação de coágulos, e está também relacionada com o aumento da pressão arterial e dos níveis de colesterol. Estas condições intensificam o risco de complicações graves, como angina, doenças coronárias, enfarte agudo do miocárdio (EAM), acidente vascular cerebral (AVC), insuficiência cardíaca congestiva e doença arterial periférica (International Diabetes Federation, 2021; Loscalzo et al., 2023).

Em Portugal, os dados indicam um aumento no número de internamentos por AVC e EAM em pessoas com DM ao longo dos últimos dez anos, verificando-se que cerca de 31% dos internamentos por AVC e cerca de 33% por EAM ocorrem em pessoas com diabetes (Sociedade Portuguesa de Diabetologia, 2023);

II. Retinopatia diabética: Trata-se de uma das principais complicações microvasculares da diabetes e uma causa evitável de cegueira em adultos. Com um impacto significativo na qualidade de vida e bem-estar do indivíduo, a retinopatia diabética (RD) resulta dos danos causados pela hiperglicemia crónica nos capilares da retina. Este processo ocorre devido ao aumento da permeabilidade capilar e à oclusão dos vasos, o que frequentemente conduz a uma diminuição ou perda permanente da visão. A hipertensão arterial (HTA) e a hipercolesterolemia, quando associadas à hiperglicemia persistente, aumentam o risco de desenvolvimento da RD (International Diabetes Federation, 2021; Loscalzo et al., 2023). A prevalência desta complicação encontra-se fortemente associada ao controlo glicémico e ao tempo de duração do diagnóstico de diabetes.

Em Portugal, apesar do aumento do número de pessoas abrangidas pelos Programas de Rastreio da Retinopatia Diabética (RD), os dados indicam que, em 2018, apenas um quarto da população inscrita nos Cuidados de Saúde Primários foi abrangido por estes programas (Sociedade Portuguesa de Diabetologia, 2023). A mesma fonte destaca que as atividades de rastreio foram significativamente impactadas pelo período pandémico, registando uma redução superior a 50% em 2020.

III. Nefropatia: A hiperglicemia crónica, característica da diabetes mellitus, induz diversas alterações ao nível renal, incluindo a hiperfiltração, que é um forte preditor de doença renal, e mudanças morfológicas no rim que resultam numa redução da sua

superfície de filtração. Estes danos microvasculares comprometem progressivamente a função renal, podendo culminar na falência total do órgão (International Diabetes Federation, 2021; Loscalzo et al., 2023). A associação entre hiperglicemia, hipertensão e insuficiência renal está amplamente documentada na literatura, sendo evidente que, enquanto a hiperglicemia provoca danos renais que aumentam o risco de hipertensão, esta última contribui frequentemente para a progressão da doença renal crónica. Dependendo da gravidade da condição renal, os custos associados a esta complicação podem ser extremamente elevados, podendo ser necessário, em estádios avançados, recorrer a técnicas de substituição da função renal, como a diálise ou o transplante renal (International Diabetes Federation, 2021; Loscalzo et al., 2023).

Em Portugal, a prevalência da DM nos doentes com doença renal crónica tem- se mantido constante, apresentando valores de cerca de 28% no ano de 2021 (Sociedade Portuguesa de Diabetologia, 2023).

IV. Neuropatia e pé diabético: A hiperglicemia persistente provoca danos em todo o sistema nervoso periférico, tornando a neuropatia uma complicação comum na diabetes (International Diabetes Federation, 2021; Loscalzo et al., 2023). A gravidade da neuropatia pode variar desde lesões impercetíveis até situações mais graves, como ulcerações, infeções severas e, em última instância, amputações. Além disso, a neuropatia pode causar disfunções eréteis, disfunções cardíacas autonómicas, bem como problemas digestivos e urinários. A neuropatia diabética resulta em danos nos nervos por todo o corpo, afetando as funções sensoriomotoras e autonómicas. A neuropatia periférica é a forma mais prevalente de neuropatia diabética, afetando os nervos distais dos membros, particularmente dos pés, o que leva a alterações de sensibilidade, caracterizadas por sensações anormais e dormência progressiva. Estas alterações favorecem o aparecimento de úlceras que, se não forem detetadas e tratadas atempadamente, podem evoluir para infeções graves, podendo resultar em amputações menores (parte do pé) ou maiores, ao nível da coxa, perna ou tornozelo (Bakker et al., 2016; International Diabetes Federation, 2021). O risco de amputação é 10 a 20 vezes superior em pessoas com DM em comparação com indivíduos sem esta patologia.

O pé diabético constitui uma das complicações mais graves e complexas da diabetes e surge devido às alterações provocadas pela neuropatia periférica e pelos problemas na circulação vascular periférica. É uma das principais causas de sofrimento pessoal e

familiar, sendo responsável por cerca de 70% das amputações não traumáticas dos membros inferiores nos países industrializados (International Diabetes Federation, 2017). O tratamento desta complicação gera custos elevados para os sistemas de saúde e constitui a principal razão de internamento das pessoas diagnosticadas (Bakker et al., 2016).

Em Portugal, no período de 2017 a 2021, o número total de episódios de amputações dos membros inferiores em pessoas com diabetes manteve-se relativamente estável. No entanto, os dados indicam um aumento das amputações major (Sociedade Portuguesa de Diabetologia, 2023). A mesma fonte indica que a letalidade intra-hospitalar associada a estas amputações, especificamente nas pessoas com diabetes, reflete uma tendência de decréscimo, particularmente nos episódios de amputações major.

V. Complicações orais: a hiperglicemia aumenta o risco de complicações orais, sendo que a prevalência de doença periodontal é superior em pessoas com DM em comparação com aquelas sem a patologia (International Diabetes Federation, 2021). O mau controlo glicémico favorece o aparecimento de cáries, gengivites, periodontites, disfunções das glândulas salivares, doenças da mucosa, infeções orais e problemas de sensibilidade oro-facial. As periodontites são a principal causa de perda dentária e estão associadas a um aumento do risco de doenças cardiovasculares.

2. LITERACIA EM SAÚDE DO ADULTO COM DIABETES

A diabetes é uma condição crónica de etiologia multifatorial, que exige a implementação de um regime terapêutico abrangente e cuidadosamente estruturado de forma a garantir a sua gestão efetiva. Esta inclui a adoção de hábitos de vida saudáveis, como uma alimentação equilibrada e a prática regular de atividade física, bem como a adesão ao regime terapêutico medicamentoso prescrito, com o intuito de alcançar o equilíbrio metabólico e prevenir complicações (American Diabetes Association, 2023).

Após o diagnostico de diabetes, a pessoa enfrenta a necessidade de realizar mudanças significativas na sua rotina diária, que incluem a adoção de comportamentos e atividades de autogestão essenciais para a monitorização e controlo efetivo da doença (Direção Geral da Saúde, 2017). Nesse contexto, a literacia em saúde desempenha um papel fundamental, sendo definida como a capacidade de obter, processar e compreender informações básicas de saúde para tomar decisões informadas sobre a sua gestão (World Health Organization, 2016). Mais do que a simples aquisição de conhecimentos, a literacia em saúde envolve o

desenvolvimento de competências práticas que permitem à pessoa interpretar e aplicar essas informações no dia-a-dia, facilitando a adesão ao tratamento, a prevenção de complicações e a melhoria da qualidade de vida (Sørensen, 2022). No caso das pessoas com diabetes, níveis adequados de literacia em saúde são fundamentais para compreender a sua condição, ajustar estilos de vida, seguir os planos terapêuticos recomendados e colaborar de forma ativa com os profissionais de saúde (Sørensen, 2022).

A autogestão da diabetes, enquanto componente essencial do autocuidado, é considerada um pilar na prevenção de complicações e na manutenção da qualidade de vida da pessoa diagnosticada, (International Diabetes Federation, 2021). Segundo a Organização Mundial de Saúde (OMS), o autocuidado é a capacidade de pessoas, famílias e comunidades promoverem e manterem a sua saúde, prevenirem doenças e gerirem condições de saúde, com ou sem a intervenção de profissionais de saúde (World Health Organization, 2022b). Este conceito, amplamente referenciado por Orem, é definido por esta autora como uma prática de atividades aprendidas e realizadas pelas pessoas, de forma consciente e intencional, com o objetivo de manter a vida, a saúde e o bem-estar, destacando-se o direito e a responsabilidade de cada pessoa em gerir os próprios cuidados através de interações interpessoais e comunicação efetiva (Orem, 2001).

No contexto da diabetes, o autocuidado refere-se a um conjunto de atividades diárias essenciais para a gestão efetiva da doença, atribuindo à pessoa diagnosticada um papel ativo e central no seu bem-estar e autocontrolo (Barlow et al., 2002). Apesar dos desafios que possam surgir no quotidiano, é a pessoa diagnosticada que tem que agir (ou decidir não agir) assumindo a responsabilidade de tomar medidas necessárias para promover uma melhor saúde para si e para aqueles que de si dependem (World Health Organization, 2022a, 2022b). Este envolvimento ativo é fundamental para garantir a adesão aos regimes terapêuticos, reduzir complicações e melhorar a qualidade de vida. Na prática, traduz-se na adoção de hábitos alimentares saudáveis, com uma dieta equilibrada e adaptada às suas necessidades específicas, na prática regular de atividade física, na monitorização rigorosa da glicemia e na adesão ao regime terapêutico prescrito (American Diabetes Association, 2023; Cruz et al., 2016).

No entanto, a gestão da diabetes vai além da pessoa diagnosticada, exigindo uma estreita colaboração com profissionais de saúde, particularmente os enfermeiros, que desempenham um papel crucial no apoio, orientação e educação durante este processo complexo (Glasgow et al., 2003; International Diabetes Federation, 2021).

Tradicionalmente, o sucesso da autogestão era avaliado com base na adesão ao regime terapêutico prescrito, sendo as intervenções educativas predominantemente focadas no ensino e treino de estratégias para promover essa adesão (Cruz et al., 2016; Funnell & Anderson, 2004). Os planos de autogestão refletiam uma abordagem predominantemente biomédica, centrada nos objetivos terapêuticos e nas metas de gestão, sem avaliar adequadamente as especificidades individuais, a cultura, tradições e recursos da pessoa diagnosticada, ou o apoio familiar e comunitário existente (Cruz et al., 2016; Funnell & Anderson, 2004). No entanto, nas últimas décadas, a elevada prevalência da diabetes e das suas complicações têm evidenciado as fragilidades das abordagens exclusivamente centradas nas metas clínicas (Direção Geral da Saúde, 2021). Estas reflexões destacam que, apesar do desenvolvimento de diversas intervenções centradas na autogestão para adultos com DM, os profissionais de saúde e decisores clínicos continuam a enfrentar desafios significativos no que diz respeito à adesão ao regime terapêutico. Estas dificuldades refletem as exigências do autocuidado e das adaptações diárias impostas pela diabetes, como a administração de medicação injetável, o uso de dispositivos digitais de monitorização glicémica e a necessidade de implementar e manter hábitos saudáveis de forma consistente (Ernawati et al., 2021; International Diabetes Federation, 2021; World Health Organization, 2022b).

Este contexto evidencia a necessidade de uma abordagem holística e multidimensional, que integre os determinantes de saúde e os fatores emocionais, sociais e culturais que influenciam a autogestão, bem como o papel dos sistemas de saúde no apoio às necessidades das pessoas diagnosticadas (Cruz et al., 2016; Direção Geral da Saúde, 2021). Além disso, para melhorar a eficácia das estratégias de autogestão, é fundamental adotar modelos teóricos que contemplem estas diversas dimensões (World Health Organization, 2022b). O Modelo *Dahlgren e Whitehead* de determinantes da saúde complementa este entendimento ao demonstrar a inter-relação entre os determinantes de saúde e a importância de intervenções em vários níveis (Dahlgren & Whitehead, 2007). Este modelo fornece uma base sólida para promover a saúde de forma equitativa, sublinhando a necessidade de políticas públicas que reforcem o suporte social, assegurem o acesso a cuidados de saúde e favoreçam condições de vida saudáveis, criando um ambiente mais favorável à gestão da diabetes (Dahlgren & Whitehead, 2007).

Desta forma, as dificuldades de adesão terapêutica na diabetes não devem ser interpretadas apenas como o resultado de escolhas individuais, mas como um reflexo de múltiplos fatores**,** incluindo determinantes sociais, económicos e estruturais que influenciam o comportamento e

as oportunidades de autogestão. Uma abordagem integrativa e centrada nas necessidades reais dos indivíduos é essencial para uma gestão mais efetiva da doença**,** reduzindo as complicações associadas e promovendo a saúde global com equidade e sustentabilidade no cuidado à pessoa com diabetes (American Diabetes Association, 2023; World Health Organization, 1986, 2009). Para tal, é fundamental implementar políticas de saúde e medidas de suporte social que fomentam a participação ativa das pessoas e das suas famílias na gestão dos cuidados, através do empoderamento das comunidades.

O empoderamento, conforme definido na Carta de *Ottawa* e reafirmado na Conferência de *Nairobi*, é o processo através do qual as pessoas obtêm maior controle sobre as decisões e ações que afetam sua saúde (World Health Organization, 1986, 2009). A promoção do empoderamento pode ser entendida como um processo de conscientização em saúde, no qual a pessoa adquire uma compreensão mais profunda das suas próprias capacidades, necessidades e recursos (Campbell et al., 2021; Freire, 2018; World Health Organization, 2021).

No contexto da diabetes, o empoderamento é crucial para fomentar a autonomia, autoeficácia e responsabilidade na gestão da doença, permitindo que as pessoas diagnosticadas adquiram uma compreensão aprofundada das suas capacidades, necessidades e recursos (Hawash et al., 2024). Essa capacitação é promovida através do aumento dos níveis de literacia em saúde (LS), que fortalece a capacidade de gerir autonomamente a condição e tomar decisões informadas sobre o tratamento e o autocuidado (Ministério da Saúde, 2023a).

A LS é um conjunto de competências que capacita o acesso, a compreensão e o uso da informação para promover a saúde (Sørensen, 2022). A LS, enquanto constructo em constante evolução, tem sido descrita e classificada por diversos autores, no entanto, ainda não foi desenvolvido um modelo teórico suficientemente abrangente que consiga refletir plenamente a sua complexidade e as competências que esta envolve (Ministério da Saúde, 2019). De acordo com os modelos teóricos existentes na literatura, a LS pode ser organizada em diferentes níveis, cuja progressão permite às pessoas adquirir maior autonomia, motivação e habilidades necessárias para a autogestão da diabetes na gestão da sua saúde (Nutbeam & Lloyd, 2021).

O modelo original de Nutbeam (2000) classifica a LS em três níveis de i) Literacia funcional, que engloba as competências básicas necessárias para a vida quotidiana, como a leitura e a escrita, sendo frequentemente associada a abordagens educativas tradicionais focadas na transmissão de informações essenciais; ii) Literacia interativa, que implica uma capacidade

mais avançada de comunicação, implicando o desenvolvimento de capacidades cognitivas e comunicativas, permitindo à pessoa maior autoconfiança, motivação e capacidade para agir e participar de forma ativa na sua própria saúde e na sociedade; e iii) Literacia crítica, que envolve não só a capacidade individual de compreender conceitos e conteúdos de saúde, mas também a habilidade de navegar em sistemas de saúde complexos, aliada a um conhecimento abrangente sobre os determinantes da saúde, capacitando a pessoa para atuar sobre esses fatores a nível social e político. Este último nível é particularmente relevante para promover a resiliência e a capacidade de enfrentar adversidades socioeconómicas, tanto a nível individual como comunitário, permitindo uma intervenção efetiva sobre os determinantes de saúde (Nutbeam, 2000).

Adicionalmente, Zarcadoolas et al. (2005) definem o conceito de Literacia cultural enquanto capacidade de reconhecer e utilizar crenças coletivas, costumes, visões do mundo e identidades sociais para interpretar e agir com base em informações de saúde. Segundo este autor, uma pessoa com níveis adequados de LS é capaz de utilizar informações de saúde de forma produtiva, adaptando-as a novas situações e contextos, o que reforça a importância de uma literacia em saúde que vá além da simples compreensão, permitindo a aplicação prática e contextualizada das informações no quotidiano.

A LS, enquanto competência humana complexa e adaptativa, evolui de forma progressiva ao longo da vida, sendo influenciada por diversos fatores, como contexto sociocultural, políticas públicas, características pessoais e experiências de vida (Alexandre et al., 2021; Espanha et al., 2016; Ministério da Saúde, 2023b; Nutbeam, 2000; Zarcadoolas et al., 2005). Pessoas com LS adequada têm maior facilidade em aceder, avaliar e aplicar informações de saúde, sendo capazes de formar juízos informados e tomar decisões adequadas (Sørensen, 2022).

Estas decisões incluem páticas essenciais para a gestão da diabetes, como a monitorização constante dos níveis de glicose, o controlo de fatores de risco e a adoção de comportamentos saudáveis, tais como o exercício físico regular, a gestão do stress e cessação tabágica (Ministério da Saúde, 2023a, 2023b). Além disso, níveis elevados de LS facilitam a comunicação entre as pessoas diagnosticadas e os profissionais de saúde, promovendo uma parceria ativa na tomada de decisões relativas ao tratamento e à gestão da doença (Espanha et al., 2016; Sørensen, 2022).

O desenvolvimento da LS não só promove a autonomia**,** como reforça o empoderamento da pessoa com diabetes, capacitando-a a adaptar comportamentos de saúde às necessidades específicas de cada fase da doença e a participar de forma proativa na sua gestão.

Apesar de a promoção da LS ser uma prioridade nas políticas de saúde, a evidência demonstra que, embora essencial, a LS isoladamente não assegura a gestão efetiva da diabetes (International Diabetes Federation, 2021). Fatores comportamentais e contextuais modificáveis, como os hábitos alimentares e o acesso limitado a recursos, destacam a necessidade de complementar a LS com estratégias que reduzam disparidades e promovam o acesso equitativo a recursos e oportunidades nos diferentes contextos sociais e económicos (International Diabetes Federation, 2023; Ministério da Saúde, 2023a; RobatSarpooshi et al., 2020). Assim, a gestão efetiva da diabetes exige uma abordagem integrada, que combine a capacitação individual com ações estruturais que favoreçam condições mais justas e inclusivas.

3. O PAPEL DA FAMÍLIA NA GESTÃO DA DIABETES MELLITUS

A família, enquanto fonte primária de suporte e partilha de informação em saúde, desempenha um papel fundamental ao longo do ciclo de vida dos seus membros, influenciando diretamente os seus comportamentos de saúde e sendo, por sua vez, influenciada pelos processos de saúde-doença vivenciados por cada um dos membros (Kaakinen et al., 2018; Shajani & Snell, 2019). Este papel é frequentemente desafiado pelas diferentes fases da vida, e pelas mudanças impostas por condições de saúde, exigindo, muitas vezes, uma reorganização das dinâmicas e relações familiares (Kaakinen et al., 2018; Shajani & Snell, 2019).

Este impacto torna-se particularmente evidente no caso do diagnóstico de DM em um dos membros da família, cuja gestão impõe uma adaptação significativas nas rotinas e dinâmicas familiares, com repercussões no bem-estar emocional e financeiro de todos os envolvidos (Pamungkas & Chamroonsawasdi, 2020; Pamungkas et al., 2017). A gestão da DM exige não só a adesão a um regime terapêutico rigoroso, mas também a implementação de mudanças significativas no estilo de vida, que, embora essenciais, são frequentemente complexas e exigentes para a pessoa diagnosticada (World Health Organization, 2020, 2022a).

Neste contexto, a literatura tem vindo a destacar a importância do suporte e envolvimento familiar, que abrange não apenas no âmbito instrumental - incluindo auxílio em tarefas domésticas, transporte para consultas médicas, suporte na administração de medicamentos e na monitorização dos níveis de glicose - como o apoio emocional (Bennich et al., 2019; Rosland et al., 2015). Este último é especialmente valorizado pela sua estreita associação com o bem-estar psicológico e a adesão ao tratamento, sendo essencial para mitigar os efeitos negativos do diagnóstico de diabetes, como o aumento dos níveis de stress, ansiedade e sentimentos de isolamento (Lee, 2018; Schwarzer & Knoll, 2007).

A autogestão da diabetes ocorre, em grande parte, no contexto familiar, tornando o envolvimento ativo da família, em colaboração com os profissionais de saúde, um elemento essencial para que o adulto diagnosticado compreenda e enfrente os desafios associados à doença (Pamungkas & Chamroonsawasdi, 2020). O suporte familiar desempenha um papel determinante, não apenas na adaptação psicológica, mas também na adesão ao regime terapêutico, ao proporcionar um ambiente de encorajamento e estabilidade que favorece os comportamentos de autocuidado (Pamungkas et al., 2017).

A evidência científica indica que o envolvimento familiar está associado a melhorias significativas nos resultados clínicos, incluindo um melhor controlo glicémico, uma maior adesão ao tratamento e à sustentabilidade dos comportamentos de autogestão, reforçando a importância de integrar a família nas estratégias de gestão da diabetes (American Diabetes Association, 2023).

O envolvimento familiar, sendo um elemento crucial para a autogestão efetiva da diabetes, não deve ser limitado ao contexto doméstico, mas sim integrado de forma ativa nas estratégias de cuidado, definidas nas consultas de rotina relativas à gestão da diabetes, e estendido para programas educativos em grupo, proporcionando uma rede de suporte mais robusta e abrangente ao adulto diagnosticado (Himmelstein & Puhl, 2021).

As intervenções focadas na díade — composta pelo adulto diagnosticado e pela sua família — têm demonstrado ganhos em saúde significativos, incluindo melhor controlo glicémico, maior adesão ao regime terapêutico e às mudanças no estilo de vida, assim como redução de sintomas psicossociais (redução de sintomas de depressão e stress e aumento da autoeficácia), melhor funcionamento familiar e um maior equilíbrio entre as necessidades reais das pessoas e a procura/utilização dos serviços de saúde (Freire, 2018; Ministério da Saúde, 2022, 2023a; Thirsk & Schick-Makaroff, 2021; Torenholt et al., 2014).

Contudo, na evidência existente, persistem lacunas significativas no que diz respeito ao suporte familiar ao adulto com diabetes, uma vez que esta temática é frequentemente abordada de forma mais abrangente em estudos centrados em crianças e adolescentes com DM. Este foco deve-se, em grande parte, ao seu elevado nível de dependência parental destes grupos etários para a gestão diária da doença, relegando a atenção ao envolvimento familiar em adultos para um plano secundário, na investigação e na prática clínica, apesar da sua importância na promoção da adesão terapêutica e na sustentabilidade dos comportamentos de autocuidado (Soares et al., 2024; Yamaguchi et al., 2023).

Paralelamente, os adultos diagnosticados com diabetes enfrentam frequentemente o estigma associado à doença, frequentemente percecionada como resultado de escolhas de vida inadequadas, o que contribui para o seu isolamento social (Himmelstein & Puhl, 2021). Este estigma pode dificultar não só a procura de apoio por parte dos familiares, mas também levar à desvalorização do envolvimento familiar como um fator determinante para o sucesso na gestão da diabetes. Consequentemente, verifica-se uma fragilização das redes de suporte emocional e instrumental fundamentais para a autogestão e para o bem-estar da pessoa diagnosticada (Himmelstein & Puhl, 2021).

Uma análise das intervenções educativas desenvolvidas com a díade revela que o foco principal destas iniciativas está centrado em estratégias que promovem o aumento do conhecimento dos membros família sobre a diabetes e no desenvolvimento de competências para o suporte instrumental às atividades diárias de gestão da DM (Thirsk & Schick-Makaroff, 2021). Contudo, esta ênfase na gestão clínica pode levar os enfermeiros a negligenciar aspetos cruciais do bem-estar emocional e psicossocial do adulto diagnosticado e dos seus familiares (Soares et al., 2024).

O foco predominantemente biomédico nas intervenções pode ter implicações significativos no envolvimento familiar, resultando em duas respostas opostas: por um lado, a recusa dos familiares em participar ativamente na gestão da doença; por outro, um envolvimento excessivo**,** que pode incluir comportamentos de infantilização do adulto com diabetes ou até a atitudes de obstrução (Alexandre et al., 2021; Bender et al., 2017; Burner et al., 2018). Estas dinâmicas, frequentemente descritas pelos adultos diagnosticados como um obstáculo à adoção de novos hábitos saudáveis, podem ser explicadas pela falta de atenção de profissionais e investigadores às dinâmicas familiares, aos conflitos internos, ao suporte emocional e às crenças da família. Adicionalmente, o stresse causado pelo diagnóstico de diabetes é outro fator que contribui para estas dificuldades (Mayberry et al., 2019; Mayberry & Osborn, 2014; Zhang et al., 2022).

Outra lacuna identificada na revisão bibliográfica diz respeito à limitada utilização de instrumentos de avaliação familiar que sejam validados e culturalmente adaptados ao contexto da gestão da diabetes em adultos (Soares et al., 2023). Esses instrumentos são essenciais, uma vez que fornecem uma base sólida não apenas para avaliar a efetividade das intervenções, mas também para personalizar as estratégias de gestão da doença, ajustando-as às dinâmicas e necessidades específicas de cada família.

A avaliação da família utilizando instrumentos validados fiáveis e culturalmente adaptados para o contexto do adulto com diabetes é indispensável para uma abordagem holística e efetiva. Para além de reconhecer e apoiar as necessidades dos familiares e os desafios emocionais, físicos e sociais impostos pelo diagnóstico, esta avaliação contribui para a criação de um ambiente de suporte genuíno. Este processo assegura que o bem-estar dos familiares seja valorizado em paralelo com o da pessoa diagnosticada, promovendo uma intervenção equilibrada, equitativa e orientada para o empoderamento de todos os envolvidos (Soares et al., 2024). Ao integrar as necessidades e perspetivas da família, esta abordagem reforça a coesão e a eficácia das estratégias de gestão da diabetes, beneficiando o contexto global de cuidados.

4. INTERVENÇÕES PSICOEDUCATIVAS DE ENFERMAGEM

A gestão das doenças não transmissíveis, especificamente da DM, representa um desafio profundo para os profissionais de saúde, cujas práticas clínicas têm sido tradicionalmente centrados no tratamento de doenças agudas (Devaux et al., 2019; International Diabetes Federation, 2021).

A prática de enfermagem tem vindo a evoluir para responder às necessidades crescentes e complexas das pessoas com DM, cuja prevalência crescente impõe novos desafios à prática clínica e à investigação, exigindo dos enfermeiros uma adaptação constante às necessidades das pessoas diagnosticadas (International Diabetes Federation, 2021). Neste contexto, torna-se imprescindível que os profissionais de saúde adotem abordagens que vão além da definição de metas clínicas, integrando intervenções que promovam o empoderamento da pessoa diagnosticada e sua família, e incentivem o seu papel ativo na gestão da sua saúde (American Diabetes Association, 2023).

A complexidade da DM, associada a fatores sociais, emocionais e comportamentais, exige que os enfermeiros desempenhem um papel central nos desenvolvimentos de intervenções personalizadas e na criação de redes de suporte que contribuam para uma gestão sustentável da doença (Alexandre et al., 2021; International Diabetes Federation, 2021). Estas abordagens mais abrangentes não só favorecem a sustentabilidade dos sistemas de saúde, mas também têm um impacto direto na qualidade de vida dos envolvidos (Alexandre et al., 2021; International Diabetes Federation, 2021).

Os enfermeiros, especialmente os especialistas em saúde comunitária e saúde pública, desempenham um papel crucial na promoção do autocuidado, pela sua proximidade às pessoas, famílias e comunidades, e às suas competências específicas em educação para a

saúde (Ordem dos Enfermeiros, 2018). Esta posição privilegiada permite-lhes identificar as necessidades específicas, coordenar as intervenções educativas e articular-se com *stakeholders*, assegurando a continuidade dos cuidados e a implementação de estratégias adaptadas aos contextos individuais e comunitários (Ordem dos Enfermeiros, 2018).

Enquanto facilitadores de mudança, o papel dos enfermeiros vai para além da intervenção clínica direta, estendendo-se à capacitação das pessoas diagnosticadas com diabetes e das suas famílias, promovendo a sua literacia em saúde e a adesão a comportamentos de autogestão sustentáveis (American Diabetes Association, 2022; American Diabetes Association, 2023). Esta abordagem não só fortalece o empoderamento individual e coletivo, mas também contribui para a redução das desigualdades em saúde, ao assegurar que os cuidados sejam personalizados (Alghamdi et al., 2022; Jiang et al., 2022).

A transformação do paradigma da prática de enfermagem, de um modelo paternalista e predominantemente biomédico, para uma abordagem participativa e empoderadora, deve também refletir-se na formação dos enfermeiros (Baig et al., 2015). Esta mudança é fundamental para capacitar os enfermeiros a agirem enquanto facilitadores do empoderamento da díade, promovendo uma reflexão conjunta sobre as necessidades e aspirações das pessoas diagnosticadas e das suas famílias (Hawash et al., 2024).

A prática de enfermagem deve alinhar-se com os princípios de empoderamento estabelecidos pela Carta de *Ottawa*, com o Código Deontológico da profissão e com os Objetivos de Desenvolvimento Sustentável (ODS), dando resposta às metas definidas pelo Plano Nacional de Saúde 2021-2030 (Ministério dos Negócios Estrangeiros, 2017; Ordem dos Enfermeiros, 2005; Sachs et al., 2023; World Health Organization, 1986). Este alinhamento implica o fortalecimento dos sistemas de apoio familiar e a promoção de resultados em saúde equitativos e sustentáveis, garantindo que as intervenções de enfermagem atendam às necessidades específicas das pessoas e comunidades, ao mesmo tempo que contribuem para a redução das desigualdades em saúde (Ministério dos Negócios Estrangeiros, 2017; Ordem dos Enfermeiros, 2005; Sachs et al., 2023; World Health Organization, 1986).

Os enfermeiros, de acordo com o Código Deontológico, têm o dever ético de respeitar a dignidade, a autonomia e os valores dos seus utentes e suas famílias, promovendo uma prática humanizada e centrada nas pessoas (Decreto-Lei nº 104/98, 2016). Este princípio ético está intrinsecamente alinhado com o conceito de empoderamento, no qual as famílias são reconhecidas como fundamentais na gestão de doenças crónicas como a diabetes.

Ao envolverem ativamente as famílias no cuidado, os enfermeiros contribuem diretamente para o ODS 3 – “Saúde e Bem-estar”, promovendo uma vida saudável e o bem-estar para todos, ao mesmo tempo que ajudam a reduzir a mortalidade prematura e os anos de vida potenciais perdidos devido doenças não transmissíveis, como a DM. Além disso, estas intervenções alinham-se também contribuem para o ODS 10 – “Redução das Desigualdades”, ao garantir cuidados de saúde equitativos e acessíveis a diferentes populações.

Assim, desenvolver intervenções fundamentadas nestes princípios exige dos enfermeiros uma abordagem centrada na pessoa com DM e sua família, combinando a humanização dos cuidados com o compromisso de alcançar resultados sustentáveis e equitativos em saúde (American Diabetes Association, 2022; American Diabetes Association, 2023). Neste enquadramento, o suporte social, com destaque para o suporte familiar, surge como um fator determinante para o sucesso das intervenções e para a apontado na literatura como um fator essencial para o sucesso das intervenções e à sustentabilidade dos comportamentos de autogestão (McEwen et al., 2019; Pamungkas et al., 2017; Soares et al., 2024). Assim, torna-se imprescindível implementar abordagens que integrem a família e o suporte social na gestão da DM, reconhecendo o seu papel crucial na adesão ao tratamento e na gestão efetiva da doença, fornecendo uma base sólida para o desenvolvimento de intervenções educativas de impacto.

O cuidar o adulto com diabetes e a sua família, garantindo uma gestão efetiva da diabetes, requer uma resposta coordenada que promova a articulação entre profissionais de saúde e decisores clínicos, alinhando estratégias que respondam de forma abrangente às necessidades dos envolvidos Para além do controlo clínico, os cuidados devem incorporar práticas direcionadas à promoção da qualidade de vida e ao fortalecimento das competências de autogestão, fundamentais para prevenir complicações e melhorar os resultados em saúde (American Diabetes Association, 2022; American Diabetes Association, 2023). A gestão da diabetes e das possíveis complicações associadas exige que os cuidados de saúde integrando práticas focadas na promoção da qualidade de vida e no fortalecimento das competências de autogestão do adulto e da sua família (International Diabetes Federation, 2021).

As recomendações atuais sublinham quatro momentos cruciais para a educação e suporte na autogestão da diabetes, nomeadamente: o momento do diagnóstico; anualmente e/ou sempre que as metas definidas não estão a ser atingidas; quando surgem novos fatores que possam precipitar complicações; e durante transições nos cuidados ou nas fases do ciclo de vida (Powers et al., 2020) As intervenções educativas são, nesse contexto, essenciais e devem ser

contínuas, ajustando-se à evolução da diabetes, às necessidades e às circunstâncias especificas de vida da pessoa diagnosticada. Num processo contínuo e adaptativo, a implementação de intervenções educativas deve acompanhar as necessidades, os objetivos e as circunstâncias de vida da pessoa diagnosticada, bem como a evolução da diabetes (Powers et al., 2020)

Este processo dinâmico promove a autoestima, autoeficácia, autodeterminação e autonomia, incentivando comportamentos de saúde ajustados às realidades e especificidades individuais e familiares. Adicionalmente, procura equilibrar a utilização dos serviços de saúde com as necessidades reais da pessoa, contribuindo para uma gestão mais eficiente da doença (Freire, 2018; Ministério da Saúde, 2022, 2023a). Ao centrar-se no adulto com DM e na sua família, esta abordagem permite não só uma melhor adaptação aos desafios impostos pela diabetes, mas também promove um equilíbrio entre as necessidades clínicas e as dimensões sociais e emocionais, essenciais para um cuidado de saúde verdadeiramente holístico.

De forma a assegurar a sustentabilidade e a continuidade destas intervenções ao longo do ciclo de vida da pessoa diagnosticada, é indispensável que estas estejam articuladas com um planeamento de saúde estruturado, garantindo não apenas a sua eficácia imediata, mas também a sua coerência e impacto a longo prazo (American Diabetes Association, 2023; Powers et al., 2020b; Tavares, 1990).

4.1. Metodologias Educativas: Estratégias e Conteúdos

As metodologias aplicadas na área da saúde são diversas e devem ser adaptadas às necessidades e especificidades da população - alvo, assim como dos seus diferentes contextos. Cada uma delas oferece abordagens distintas para a apropriação de conhecimento e para o desenvolvimento de competências, sendo utilizadas com o objetivo de capacitar e empoderar os participantes na gestão da sua saúde. Entre as principais metodologias destacam-se a metodologia expositiva, a metodologia ativa e a metodologia interrogativa (Gouveia et al., 2007; Laverack, 2008).

A metodologia expositiva, amplamente utilizada em contextos educacionais formais, incluindo o ensino da saúde, promove a aquisição de conhecimentos essenciais, especialmente em saúde (Gouveia et al., 2007).

Nesta abordagem diretiva, o enfermeiro assume um papel central, transmitindo informações fundamentais de forma estruturada e clara, enquanto os participantes adotam um papel mais passivo, focado na receção da informação (Gouveia et al., 2007). Há, desta forma, uma clara assimetria de conhecimentos entre o profissional de saúde e os participantes, sendo o

profissional o principal responsável pela transmissão da informação que ele considera essencial para promover mudanças no estilo de vida e nos comportamentos dos participantes (Gouveia et al., 2007).

Incluem-se também estratégias práticas, como demonstrações e treino de competências. No contexto da diabetes, esta metodologia é útil para ensinar conceitos básicos, como os mecanismos da glicemia e a importância da adesão ao tratamento, além de técnicas específicas, como a monitorização da glicemia e a administração de insulina. O objetivo é oferecer uma base sólida para que os participantes apliquem esses princípios no autocuidado, corrigindo mitos e promovendo o entendimento fundamental da doença (Gouveia et al., 2007; Laverack, 2008).

Embora fundamental para transmissão de conhecimentos específicos, a metodologia expositiva apresenta limitações em termos de promoção da autonomia e do envolvimento ativo, sendo mais adequada para fases iniciais do diagnostico de diabetes, ou em momentos críticos, nos quais o foco conceitos-chave de forma rápida e clara (Laverack, 2008).

As metodologias de intervenção ativas são promovem um papel dinâmico e participativo dos intervenientes, com os profissionais de saúde a preparar e moderar as sessões (Gouveia et al., 2007). Nessas metodologias, os participantes estão no centro do processo de aprendizagem, sendo incentivados a envolverem-se ativamente, o que promove a sua autonomia, pensamento crítico e aplicação prática dos conhecimentos adquiridos nas suas vivências quotidianas. Diferentemente das metodologias expositivas, em que os participantes assumem um papel passivo, as metodologias ativas estimulam a construção do conhecimento através de experiências interativas, resolução de problemas e colaboração. Este processo de parceria efetiva permite que os participantes compreendam a sua "realidade objetiva e desafiadora, sobre a qual devem incidir a sua ação transformadora" (Freire, 2018, p. 44).

No contexto da saúde, esta abordagem facilita a partilha de experiências, desafios e conhecimentos práticos sobre a gestão da condição de saúde, enquanto os profissionais oferecem informações técnicas e orientações baseadas em evidências. O profissional atua como facilitador, incentivando a discussão e fornecendo suporte, enquanto os participantes utilizam os seus conhecimentos e experiências pessoais na resolução dos problemas (Gouveia et al., 2007). Estas metodologias, associadas a maior adesão, promovem a autonomia e a capacidade dos participantes de gerir a própria saúde de forma efetiva, com o profissional a apoiar, facilitando a reflexão crítica e clarificação de dúvidas (Gouveia et al., 2007; Laverack, 2008).

No âmbito das metodologias ativas, destacam-se as intervenções psicoeducativas, consideradas promissoras e seguras quando fundamentadas em evidência científica sólida e teorias bem estruturadas (Law et al., 2019; Martire et al., 2004; Shajani & Snell, 2019). Estas intervenções destacaram-se pela sua abordagem holística e contínua, ultrapassando a simples aquisição de conhecimentos específicos ao integrarem estratégias focadas na promoção de comportamentos saudáveis e no bem-estar mental, especialmente em momentos de desequilíbrio físico e emocional (Cheng et al., 2022). A evidência disponível indica que as intervenções psicoeducativas têm impacto significativo, proporcionando benefícios a curto prazo, como a redução dos sintomas de ansiedade e depressão, melhoria da qualidade de vida e o aumento da autoeficácia, os quais, por sua vez, contribuem para a melhoria da saúde física a longo prazo (Cheng et al., 2022; Ong et al., 2023).

4.1.1. Estratégias Educativas

A escolha das estratégias educativas adequadas é fundamental para o sucesso das intervenções em saúde, devendo ser cuidadosamente adaptada ao contexto e às necessidades dos participantes (Tavares, 1990). Em metodologias expositivas, centradas na figura do "professor" e na relação vertical de transmissão de conhecimento, os profissionais de saúde utilizam estratégias de comunicação direta, como apresentações estruturadas com ou sem apoio audiovisual, para transmitir informações essenciais de forma clara e objetiva (Gouveia et al., 2007; Laverack, 2008). Além disso, estas metodologias podem incluir jogos interativos em grupo, que incentivam uma participação mais ativa dos participantes e promovem a aplicação prática dos conhecimentos adquiridos de forma mais dinâmica e envolvente (Nasrulloh et al., 2024). O uso de jogos tradicionais e interativos é amplamente descrito na literatura, estando positivamente associado a melhorias no bem-estar físico e na saúde mental dos participantes (Nasrulloh et al., 2024). Estas atividades simulam situações reais de gestão de saúde ou de escolhas diárias relacionadas com a diabetes, com o feedback imediato e orientação do profissional de saúde, reforçando a aprendizagem através da experiência direta (Nasrulloh et al., 2024).

As metodologias ativas, para além dos jogos interativos, promovem as sessões em grupo e a formação por pares (Peimani et al., 2018; Zhao et al., 2019). Nestas sessões, são promovidos momentos de partilha entre pessoas com experiência direta na diabetes, enquanto peritos da sua própria saúde, sobre as suas vivências e estratégias de autocuidado, criando um ambiente de aprendizagem colaborativa. A literatura sugere que o apoio mútuo neste contexto facilita a adesão ao tratamento e a incorporação de novos comportamentos de saúde (Peimani et al.,

2018). A efetividade da entrevista motivacional e definição de objetivos SMART (Específicos, Mensuráveis, Atingíveis, Relevantes e Temporais), são igualmente destacadas como estratégias efetivas (Bjerke & Renger, 2017; Miller & Rollnick, 2002)

A entrevista motivacional, centrada nas pessoas, visa promover mudanças comportamentais através da exploração e resolução de ambivalências (Miller & Rollnick, 2002). Esta abordagem revela-se especialmente efetiva para os participantes que desejam transformar os seus comportamentos, mas que necessitam de motivação adicional para implementar essas mudanças (Ramadan & Ali, 2019). Utilizando técnicas como a escuta ativa, perguntas abertas e reflexão, os enfermeiros, enquanto facilitadores da mudança, incentivam os participantes a explorar sentimentos contraditórios em relação às alterações necessárias no seu estilo de vida e a identificar soluções adequadas, fortalecendo a sua motivação e compromisso com a mudança (Miller & Rollnick, 2002). Este diálogo contínuo e bidirecional transforma a entrevista motivacional numa poderosa ferramenta de empoderamento, colocando a pessoa no centro do processo da mudança dos seus comportamentos de saúde, permitindo-lhe em simultâneo articular as suas motivações e superar as eventuais resistências internas à mudança (Miller & Rollnick, 2002; Ramadan & Ali, 2019; Uludağ & Kaşikçi, 2024).

Embora a entrevista motivacional seja amplamente reconhecida no contexto da diabetes pela sua associação positiva com uma maior adesão ao tratamento e pela promoção dos autocuidados fundamentais para uma gestão efetiva da doença, a sua implementação requer profissionais devidamente capacitados. É essencial que estes disponham de competências avançadas em comunicação colaborativa, capazes de estabelecer uma relação empática, congruente e de parceria efetiva com os utentes, de forma a maximizar os benefícios desta abordagem (Miller & Rollnick, 2002; Ramadan & Ali, 2019; Uludağ & Kaşikçi, 2024). Esta estratégia pode ainda fazer recurso dos objetivos SMART que permite um processo estruturado e sustentável de mudança (Bjerke & Renger, 2017; Doran, 1981).

Os objetivos SMART, originalmente desenvolvidos no contexto da gestão, são reconhecidos como um padrão na formulação de metas mensuráveis e realistas, com prazos definidos e relevantes para a gestão da diabetes (Bjerke & Renger, 2017; Doran, 1981). Esta abordagem, ao promover a participação ativa e conjunta de soluções, potência a adesão ao plano de ação e facilita a transformação das intervenções educativas em mudanças concretas no autocuidado (Miller & Rollnick, 2002; Ramadan & Ali, 2019; Uludağ & Kaşikçi, 2024).

Outra estratégia descrita na literatura é a utilização de novas tecnologias. Esta estratégia, considerada inovadora e acessível surge nos programas quer como alternativa às abordagens

presenciais, quer como complemento das mesmas, facilitando o acompanhamento contínuo e a monitorização dos progressos dos participantes no cumprimento dos seus objetivos (Kerr et al., 2019; Pérez-Aldana et al., 2021).

Ferramentas como jogos online, videochamadas e reuniões em grupo oferecem um ambiente de aprendizagem dinâmico e acessível, com impacto positivo na promoção de comportamentos de autocuidado e na gestão de doenças crónicas, como a diabetes (Fleming et al., 2020). Estas tecnologias não apenas ampliam as possibilidades de interação com os profissionais e personalização das intervenções educativas, como também reforçam as redes de apoio e facilitam a partilha de experiências entre os participantes, (Asadzandi et al., 2020).

Os jogos interativos, por exemplo, permitem a aplicação prática e lúdica dos conhecimentos adquiridos, alinhando-se com os princípios da entrevista motivacional e dos objetivos SMART, criando um espaço seguro e envolvente onde as metas podem ser testadas e aperfeiçoadas (Asadzandi et al., 2020). Contudo, a eficácia destas tecnologias depende fortemente da literacia digital dos participantes (Ministério da Saúde, 2019, 2023a; Vlies, 2020). A literacia digital, entendida como a capacidade de utilizar, explorar, compreender e avaliar criticamente a informação de saúde disponibilizada digitalmente, é um fator determinante para o sucesso destas intervenções (Ministério da Saúde, 2019, 2023a; Vlies, 2020). Em Portugal, apenas cerca de 56% da população possui competências digitais adequadas, com uma percentagem ainda menor entre os mais idosos (Ministério da Saúde, 2019). Esta limitação evidencia a necessidade de estratégias educativas adaptadas às diferentes competências digitais dos utilizadores, garantindo que a inovação tecnológica seja acessível e efetiva para todos (Fleming et al., 2020). Paralelamente, é fundamental investir em investigação científica para validar e avaliar a efetividade destas ferramentas, assegurando a sua aplicação baseada em evidências, com impacto significativo na saúde e qualidade de vida dos utilizadores (Fleming et al., 2020; Kerr et al., 2019).

4.1.2. Conteúdos no Apoio à Gestão da Diabetes

De acordo com as recomendações educativas internacionais, os conteúdos das intervenções devem ser direcionados para a promoção de uma autogestão efetiva da diabetes, abrangendo não apenas os aspetos clínicos da doença, mas também fatores emocionais, psicossociais e comportamentais que influenciam diretamente o sucesso desta gestão (American Diabetes Association, 2023). Para permitiram uma gestão efetiva, esses conteúdos devem ser personalizados, considerando as necessidades específicas e o contexto de vida de cada

pessoa, capacitando-a para tomar decisões informadas e adaptar-se às exigências da diabetes ao longo da evolução da doença.

É essencial que as intervenções educativas se fundamentem numa abordagem holística, considerando os múltiplos fatores que influenciam a adesão ao regime terapêutico e a sustentabilidade das intervenções (American Diabetes Association, 2022; American Diabetes Association, 2023). Assim, além dos aspetos clínicos da diabetes e possíveis complicações associadas, as intervenções devem integrar a gestão emocional da doença e os desafios emocionais frequentemente enfrentados pelas pessoas diagnosticadas (Shuhaida et al., 2019). Estas competências emocionais, como a resiliência e a adaptação ao diagnóstico e à gestão diária da diabetes são ferramentas essenciais para a manutenção de comportamentos saudáveis e para a gestão de emoções negativos, como o stress, ansiedade e outras emoções, que comprometam a adesão ao tratamento ou agravem o estado de saúde, dificultando a manutenção de comportamentos saudáveis (American Diabetes Association, 2023).

Neste sentido, as intervenções não médicas, como o apoio psicológico, social e comportamental, têm-se revelado efetivas na gestão da diabetes, melhorando a qualidade de vida das famílias, o seu funcionamento e a gestão da doença (Zhang et al., 2022). Estas intervenções, frequentemente de caráter psicoeducativo, comportamental ou relacional, abordam de forma integrada os conteúdos relacionados com os aspetos físicos, emocionais e sociais associados à diabetes

Na definição dos conteúdos das intervenções educativas, é essencial incluir o desenvolvimento de competências biopsicossociais, com destaque para as competências de comunicação, que potenciam a capacidade dos participantes de interagir de forma efetiva com os recursos e serviços de saúde (Ministério da Saúde, 2019, 2023a, 2023b). Os conteúdos devem ser cuidadosamente estruturados para promover uma progressão no desenvolvimento de competências orientando os participantes ao longo de um percurso que culmina na aquisição da dimensão crítica da literacia em saúde (Ministério da Saúde, 2019, 2023a, 2023b).

Este processo gradual assegura que os participantes adquiram inicialmente conhecimentos e habilidades fundamentais, evoluindo progressivamente para a construção de competências mais complexas e analíticas (Sørensen, 2022). Ao serem empoderados para assumir um papel mais ativo e reflexivo na gestão da sua saúde, os participantes tornam-se capazes de avaliar criticamente as informações e tomar decisões informadas, sempre com o suporte adequado

dos profissionais de saúde. Os conteúdos, por sua vez, devem ser adaptados à evolução dos participantes ao longo do processo, garantindo a sua relevância e eficácia.

A promoção da LS, especialmente na sua dimensão crítica, capacita as pessoas com DM e as suas famílias a tornarem-se mais conscientes, informadas e habilitadas a tomar decisões fundamentadas para a sua saúde. Este processo fomenta um diálogo contínuo e colaborativo entre os participantes e os profissionais de saúde, promovendo uma gestão partilhada nos diferentes níveis de cuidados (Ministério da Saúde, 2019, 2023a, 2023b).

CAPÍTULO II: IDENTIFICAÇÃO DE UMA TEORIA

1. MODELOS DE AVALIAÇÃO E INTERVENÇÃO FAMILIAR DE *CALGARY*

Os cuidados de enfermagem tiveram origem no ambiente familiar, onde o envolvimento da família e a compreensão dos fatores que influenciavam o processo saúde-doença eram elementos centrais e naturais (Shajani & Snell, 2019; Wright & Leahey, 2013). Historicamente, o impacto direto da família na saúde e bem-estar dos seus membros sempre esteve presente, mesmo antes de ser formalmente reconhecido como parte dos cuidados (Wright & Leahey, 2013).

Os Modelos de Avaliação e Intervenção Familiar de *Calgary* (CFAM e CFIM) emergem como um referencial teórico estruturado e amplamente validado, que orienta a prática de enfermagem no contexto familiar (Shajani & Snell, 2019). Estes modelos adotam uma abordagem holística, integrando as dimensões estruturais, funcionais e de desenvolvimento da família, permitindo uma compreensão abrangente das suas dinâmicas e necessidades (Shajani & Snell, 2019). Desenvolvido para apoiar profissionais de saúde, particularmente enfermeiros, o modelo avalia o impacto dos problemas de saúde nos membros da família e a sua influência na aceitação e resolução dos processos de saúde-doença (Wright & Leahey, 2013).

Neste contexto, a definição de família é um elemento central. Ao longo dos anos, a definição de família evoluiu, refletindo mudanças na sua formação, estrutura e dissolução (Shen et al., 2021). Várias definições têm emergido na literatura, com uma crescente ênfase na igualdade entre os seus membros, sublinhando a importância do respeito mútuo, da dignidade, da igualdade e da solidariedade que devem nortear as suas relações. Segundo os Modelos de *Calgary*, família é definida como o grupo de pessoas que se identificam como tal, independentemente de laços sanguíneos ou legais, focando-se nas relações afetivas, sociais e de suporte mútuo entre os seus integrantes (Wright & Leahey, 2013). Este conceito reconhece a família como uma entidade dinâmica, com identidade própria e autonomia, cujos membros influenciam mutuamente o seu bem-estar e desenvolvimento ao longo do tempo.

As complexas relações entre a estrutura, a função e os processos familiares levaram as autoras dos Modelos de *Calgary* a estabelecer seis fundamentos teóricos para sustentar tanto a avaliação (CFAM) quanto a intervenção (CFIM) familiar. Estes fundamentos teóricos incluem a teoria dos sistemas, a teoria da comunicação, a teoria da mudança, a biologia da cognição, o pós-modernismo e a cibernética, que serão abordados de forma muito sucinta nesta tese (Wright & Leahey, 2013). Estes referenciais oferecem uma base teórica robusta e prática para

a aplicação do modelo na prática clínica, promovendo intervenções que respondam de forma holística às necessidades das famílias:

i. **Teoria dos Sistemas**: a família é vista como um sistema complexo, no qual os membros estão interligados e influenciam-se mutuamente. Qualquer mudança num membro ou numa parte do sistema afeta o funcionamento da família como um todo e tem um impacto, em diferentes graus, em todos os outros membros. Este conceito é fundamental para a compreensão de como o enfermeiro através da implementação de intervenções pode alterar o sistema familiar. Isto é, ao implementar estas mudanças através das intervenções educativas o membro da família muda, desta forma os outros membros já não podem reagir da mesma forma, pois o comportamento daquele membro foi alterado.

   As famílias encontram-se em constante processo de transformação, o que significa que, sempre que ocorre uma alteração significativa, a família ajusta-se até alcançar um novo estado de equilíbrio. Este processo exige uma reorganização, que se distingue das formas anteriores de estrutura familiar.

   Uma família é composta por vários subsistemas, como p.e os subsistemas conjugal e fraternal. Estes subsistemas, por sua vez, são constituídos por subsistemas de pessoas. As pessoas são sistemas extremamente complexos, compostos por vários subsistemas, alguns dos quais são físicos (como o sistema cardiovascular e o sistema reprodutivo) ou psicológicos (como os sistemas cognitivo, afetivo e comportamental). Por outro lado, a família é apenas uma unidade inserida em suprassistemas maiores, como bairros, organizações ou comunidades religiosas. Uma pessoa pode pertencer a vários sistemas de papéis, como o de filha, parceira, colega, esposa, irmã, enfermeira, mãe e avó.

   Cada sistema tem uma hierarquia e fronteiras que os profissionais devem reconhecer e integrar no seu cuidar a família. Estes conceitos assumem-se como essenciais em certos grupos étnicos e tornam cada família singular.

   Desta forma, os enfermeiros devem abordar as famílias como um todo, observando as interações entre os seus membros para alcançar uma compreensão mais profunda do funcionamento individual de cada um. Não é possível compreender a pessoa sem entender como o sistema familiar funciona, pois, as partes só ganham sentido quando consideradas no contexto do conjunto. Da mesma forma, o funcionamento do todo não

pode ser totalmente compreendido sem uma análise detalhada das suas partes constituintes.

Os comportamentos dos membros da família são melhor compreendidos numa perspetiva de causalidade circular, em vez de linear. No âmbito das interações familiares, parte-se do princípio de que cada indivíduo contribui tanto para interações adaptativas como para disfuncionais. Cada membro da família tende a considerar a sua perceção do outro como correta, mas não reconhece o impacto que o seu próprio comportamento tem sobre o comportamento do outro.

ii. **Teoria da comunicação**: o estudo da comunicação foca-se na forma como as interagem uns com os outros. No contexto da família, os seus elementos trocam informações, tanto de forma verbal como não verbal. A função da comunicação na família é ajudar os membros da família a esclarecer as regras familiares relativas ao comportamento, ajudá-los a compreender o seu ambiente, explicar como os conflitos são resolvidos, promover e desenvolver a autoestima de todos os membros e modelar a expressão construtiva dos estados emocionais dentro da família como uma unidade. A comunicação pode ser verbal ou não verbal, ou seja, mesmo na ausência de comunicação verbal, ocorre comunicação não verbal, na qual as pessoas transmitem mensagens aos outros. Isto evidencia que "não comunicar" entre indivíduos é impossível. Neste sentido, o contexto revela-se determinante, uma vez que um comportamento só adquire relevância e significado quando compreendido no contexto em que ocorre.

A comunicação é transmitida através de dois canais principais: digital e analógico. A comunicação digital refere-se à comunicação verbal. A comunicação analógica abrange não apenas os tipos habituais de comunicação não verbal, como a postura corporal, a expressão facial e o tom de voz, mas também inclui a música, a poesia e a pintura. Quando existem discrepâncias entre estes dois canais de comunicação, as autoras sugerem que o enfermeiro deverá incidir a sua atenção na mensagem analógica. A comunicação tem dois níveis: o conteúdo (o que está a ser dito) e relação (informações que definem a relação das pessoas que se encontram a interagir. A comunicação familiar revela não apenas uma mensagem sobre "quem está a dizer o quê e quando", mas também transmite uma mensagem sobre a estrutura e as funções das relações familiares em termos de poder, processos de tomada de decisão, afeto, confiança e coligações.

iii. **Teoria da mudança:** O conceito de mudança no modelo teórico de *Calgary* assenta na premissa que as famílias têm a capacidade de evoluir e adaptar-se a novas situações. A mudança é uma alteração na estrutura familiar que ocorre como resposta a um acontecimento/ perturbação e tem como objetivo manter a estrutura e a estabilidade. Uma mudança no estado da família manifesta-se através de comportamentos, definindo-se dois tipos ou níveis de mudança, de primeira e de segunda ordem.

Na mudança de primeira ordem, refere-se a uma mudança de quantidade e não de qualidade. Isto é, o sistema como um todo permanece inalterado, mas os seus elementos sofrem algum tipo de mudança. Este tipo de mudança envolve a utilização das mesmas estratégias de resolução de problemas repetidamente. Se a solução para o problema for difícil de encontrar, são utilizadas mais estratégias antigas, aplicadas geralmente de forma mais vigorosa.

Contrariamente, a mudança de segunda ordem implica que hajam alterações nas regras que regem o sistema, o que leva a uma transformação estrutural do sistema e um nível diferente de funcionamento. A mudança é constantemente evolutiva nas famílias, podendo ocorrer de forma súbita e radical, ou seguir uma sequência lógica, sendo que as pessoas frequentemente não têm consciência das mesmas.

Este tipo de mudança contínua ou espontânea ocorre com a vida quotidiana e com a progressão através dos estágios de desenvolvimento individuais e familiares. Estas mudanças podem ou não ocorrer com intervenção profissional. Grandes transformações de todo o sistema familiar também podem ocorrer e ser precipitadas por eventos críticos, como doença grave, divórcio ou morte de um dos membros da família

A mudança dentro de uma família pode ocorrer nos domínios cognitivo, afetivo ou comportamental, mas a mudança em qualquer um destes domínios afeta os outros. Esta complexidade e a imprevisibilidade, impede que os enfermeiros e/ou investigadores façam correlações diretas ou previsões de mudanças de comportamento dos elementos da família após a intervenção. É fundamental que os enfermeiros cuja intervenção tem como objetivo facilitar mudanças, adotem uma perspetiva sistémica. Essa abordagem requer a observação cuidadosa das conexões entre os sistemas familiares e das interações estabelecidas entre a família e outros contextos externos (Wright & Leahey, 2013). Na prática clínica, os enfermeiros devem reconhecer que a mudança é determinada pela estrutura biopsicossocial e espiritual

de cada pessoa, incluindo as influências interpessoais, intrapessoais e ambientais que podem desencadear alterações estruturais. Além disso, a mudança é profundamente afetada pela forma como os diferentes membros da família percecionam os problemas que enfrentam. Assim, é crucial que os profissionais reconheçam a heterogeneidade de perceções dentro da família, evitando confiar exclusivamente na perspetiva de um único membro. Os enfermeiros devem valorizar e aceitar as perceções, crenças e perspetivas de todos os elementos familiares, oferecendo-lhes visões alternativas sobre as suas preocupações de saúde, doença ou problemas.

A singularidade de cada pessoa e a forma como esta é influenciada pelas intervenções educativas destacam a necessidade de adaptar e personalizar as estratégias, evitando a implementação de abordagens padronizadas para problemas específicos. Este enfoque é particularmente importante porque o profissional de saúde não consegue antecipar quais intervenções serão efetivas em determinado momento para promover mudanças em cada membro da família (Wright & Leahey, 2013).

Uma variável determinante para o processo de mudança é o contexto em que a família está inserida. O planeamento das intervenções deve considerar os recursos disponíveis e os potenciais conflitos entre diferentes sistemas, como hospitais e outros prestadores de cuidados (sistemas maiores), que podem dificultar ou mesmo inviabilizar as mudanças desejadas. Reconhecer e abordar esses conflitos é essencial para que a mudança seja possível e sustentável (Wright & Leahey, 2013).

Para que a mudança ocorra de forma efetiva, os objetivos estabelecidos entre os enfermeiros e as famílias devem evoluir em simultâneo, ser ajustados às especificidades de cada pessoa e definidos dentro de um prazo realista. Esses objetivos devem ser identificados e acordados numa parceria colaborativa, considerando os problemas que mais preocupam a família e as mudanças que esta deseja alcançar. Parte do papel do enfermeiro é apoiar a família na identificação de respostas alternativas nos domínios comportamental, cognitivo e afetivo, ajudando-a a descobrir ou a recuperar as próprias soluções para os desafios encontrados. Contudo, é importante destacar que, mesmo com a compreensão do problema que a família está a vivenciar, a solução para o mesmo não surgirá automaticamente. A partir de uma perspetiva sistémica, as soluções para os problemas emergem à medida que as crenças sobre saúde, doença, problemas e padrões de comportamento se modificam, independentemente de uma compreensão profunda ou não do tema. As autoras

sublinham a relevância de evitar a busca imediata por soluções, reconhecendo que a maioria dos problemas reside nas interações entre as pessoas, ou seja, são de natureza relacional e não em características intrínsecas das pessoas.

Os enfermeiros têm a responsabilidade de facilitar mudanças em colaboração com cada família, mas isso não significa direcionar o processo de mudança com o objetivo de alcançar um resultado específico. A família, enquanto especialista no seu próprio processo de saúde-doença, possui um conhecimento intrínseco das suas vivências, enquanto os enfermeiros, enquanto especialistas na sua área de atuação, fornecem apoio técnico e orientação. Este modelo colaborativo exige que os enfermeiros abandonem uma postura prescritiva e comportamentos de ensino tradicionais e diretivos e adotem o papel de facilitadores, permitindo que as mudanças surjam de forma orgânica e sustentável.

Essa abordagem terapêutica reforça que as mudanças sustentáveis são determinadas pelas estruturas biopsicossociais e espirituais de cada membro da família, e não pelo enfermeiro. Adotar uma postura colaborativa, sem julgamentos, promove uma relação terapêutica que valoriza a autonomia e respeita a complexidade dos processos familiares.

iv. **Biologia da cognição**: este fundamento teórico reconhece a importância das "perceções" e "interpretações cognitivas" dos vários membros da família acerca da sua realidade. Desta forma, reconhece-se que todas as pessoas têm diferentes perspetivas sobre os eventos e experiências nas suas vidas. A nossa capacidade de conhecer e entender o mundo é construída através da interação entre o nosso corpo, o ambiente e os outros. O conhecimento de acordo com os autores originais da teoria da biologia da cognição defendem que o conhecimento não é simplesmente uma representação objetiva da realidade externa, mas sim algo que se constrói a partir das experiências individuais e coletivas. No contexto do Modelo de *Calgary*, a biologia da cognição destaca a importância de compreender como os membros da família interpretam a sua realidade, incluindo a doença, e como essas interpretações afetam a forma como lidam com os desafios de saúde. Assim, os enfermeiros devem adotar uma postura aberta e curiosa, reconhecendo que cada membro da família traz consigo uma visão única e válida sobre a sua experiência de doença e de relação familiar. Essa abordagem permite que os profissionais de saúde facilitem a comunicação e o entendimento mútuo

entre os membros da família, promovendo mudanças mais efetivas e adaptadas às necessidades e realidades da família.

v. **Pós-modernismo:** as pessoas tendem a encontrar satisfação ao repensar, reexaminar e desconstruir a sua história e cultura, abordando-as sob novas perspetivas. O pós-modernismo é uma abordagem amplamente utilizada para esse fim e desafia a ideia de uma única verdade objetiva. Este conceito reconhece que existem múltiplas interpretações e narrativas possíveis sobre a realidade. Embora não possamos negar a influência da nossa história e cultura no que fomos e no que somos hoje, o pós-modernismo convida-nos a reconhecer que essas influências são dinâmicas e passíveis de reinterpretação. De igual forma, este conceito sublinha a importância de considerar as várias histórias e realidades que cada membro da família traz para a interação. Ao reconhecermos as influências anteriores e contínuas dos paradigmas modernistas e pós-modernistas nas nossas vidas, podemos aplicar esses princípios na prática da enfermagem familiar relacional, promovendo uma abordagem mais flexível e adaptada às necessidades e realidades de cada família.

vi. **Cibernética**: os sistemas familiares têm a capacidade de autorregulação, o que significa que o comportamento de cada membro influencia os outros, e essa mesma pessoa é, por sua vez, influenciado pelo comportamento dos restantes membros da família. A compreensão deste fundamento teórico evita que um único membro seja responsabilizado pelos problemas enfrentados pela família. Um exemplo comum é o ciclo de interação entre uma esposa crítica e um marido que se afasta. Esse padrão pode ser interpretado como parte de um ciclo de feedback mais amplo, que inclui as influências das famílias de origem do casal. Este processo pode reajustar o ciclo de interação direta entre o casal, ajudando a compreender melhor a dinâmica relacional. A inclusão deste conhecimento é particularmente útil em situações complexas, pois permite ao enfermeiro reconhecer que os problemas familiares são interdependentes e não podem ser atribuídos a uma única pessoa, promovendo, assim, uma intervenção mais sistémica e equilibrada.

Estes seis fundamentos teóricos proporcionam a base para uma avaliação e intervenção com a família de forma integrada e holística e combinando diferentes dimensões do cuidado.

O **Modelo de Avaliação Familiar de *Calgary* (CFAM)** é uma ferramenta teórica utilizada por enfermeiros e outros profissionais de saúde para avaliar de forma abrangente o funcionamento das famílias, especialmente quando um dos seus membros enfrenta uma condição crónica,

como a diabetes. Este modelo baseia-se numa abordagem sistémica e ecológica da família, considerando que as dinâmicas familiares são influenciadas por vários fatores internos e externos. O CFAM divide-se em três principais áreas de avaliação: Estrutural; Desenvolvimental e Funcional.

A **Avaliação Estrutural** objetiva identificar a composição da família e as suas ligações externas. Esta avaliação familiar inclui três dimensões: a **estrutura interna**, a **estrutura externa** e o **contexto**.

A **estrutura interna** inclui cinco subcategorias: a composição familiar; género; orientação sexual; ordem hierárquica; subsistemas e as fronteiras.

- A composição familiar pode ter diversos significados de acordo com o conceito de família adotado. Neste projeto de investigação família é quem eles dizem que são, independentemente dos laços sanguíneos ou legais. No contexto do adulto diagnosticado com diabetes, é determinante identificar com o adulto quem são a/as pessoas que são a sua fonte de suporte, mais especificamente na gestão da DM.
- O género na perspetiva das autoras deste modelo teórico é uma construção que parte do nosso próprio quadro de referência e inclui um conjunto de crenças ou expectativas sobre os comportamentos e experiências da mulher e do homem. Estas crenças são moldadas por influências culturais, religiosas e familiares, bem como pela classe social e orientação sexual.

  A avaliação do género é particularmente importante quando a perceção dos papéis masculinos e femininos, moldados pelas crenças sociais, culturais ou familiares são fonte de tensão na família. Isto é, quando a mulher e o homem não tem uma relação igualitária porque as suas próprias experiências e os seus contextos ditam como ambos se devem sentir, pensar ou agir na estrutura familiar.

  No contexto da gestão da diabetes, a evidência tem demonstrado a influência do género e dos papéis que lhe estão associados e a gestão da doença e complicações associados (Ciarambino et al., 2022).
- A orientação sexual inclui tanto as populações de maioria sexual como os de minoria sexual. A avaliação do género assume-se como fundamental quando a diferença na orientação sexual da pessoa se assume como preconceito e tem potencial para prejudicar a pessoa e a família e a prestação de cuidados de saúde.
- A ordem hierárquica numa família refere-se à posição relativa das crianças em função da sua idade e género. Esta subcategoria está relacionada com a dinâmica familiar que

pode ser influenciada pela posição de cada filho dentro da família, como ser o mais velho, o mais novo ou o filho do meio. Cada uma dessas posições pode trazer responsabilidades, expectativas e papéis específicos, influenciando a forma como os membros da família interagem entre si.

- Subsistemas: este termo refere-se aos diferentes níveis de diferenciação dentro do sistema familiar, sendo através destes que a família desempenha essas funções. Como exemplo de subsistemas temos as díades "marido-mulher", ou "mãe-filho".
  A delimitação de cada subsistema pode ser realizado por geração, sexo, interesses, função ou história, sendo a capacidade de se adaptar às exigências dos diferentes níveis de subsistemas, uma competência fundamental para cada membro da família. Assim, uma mulher de 65 anos pode ser simultaneamente avó, mãe, esposa e filha dentro da mesma família. Esta subcategoria deverá ser avaliada pelos enfermeiros de forma a identificarem se existem limites estabelecidos entre gerações, ou se estes os diferentes subsistemas e as suas funções específicas contribuem para conflitos ou níveis aumentados de stress familiar.
- Limites: os sistemas familiares e os respetivos subsistemas possuem limites, cuja função é definir, proteger a diferenciação de cada sistema e/ou subsistema. Os limites podem ser difusos, rígidos ou permeáveis. À medida que os limites se tornam difusos, a diferenciação do sistema familiar diminui. Desta forma, como as fronteiras entre os membros da família estão pouco definidas, eles tornam-se emocionalmente muito próximos, com um maior sentido de presença, mas com uma menor autonomia individual. Contrariamente, quando os limites são rígidos, os subsistemas tendem a tornar-se mais desconectados entre si, o que resulta em papéis rígidos de cada membro da família. Os limites claros e permeáveis permitem uma flexibilidade adequada entre subsistemas, possibilitando a modificação das regras quando necessário. Importa referir que estes limites tendem a mudar ao longo dos anos e tornar-se até ambíguos durante a reorganização da família. Nesta subcategoria, as autoras argumentam que, ao trabalhar com famílias de diferentes culturas, etnias, classes sociais ou em contextos rurais, os enfermeiros, ao fomentar a criação e o fortalecimento de outros laços centrais, proporcionam benefícios acrescidos para o bem-estar e funcionamento da família. Estes laços centrais integram as relações que oferecem suporte emocional, social e, por vezes, financeiro, e que influenciam de maneira direta o bem-estar e o funcionamento de cada membro da família.

A **estrutura externa** inclui duas subcategorias: a família alargada e os sistemas maiores.

- A <u>família alargada</u>: esta subcategoria engloba a família de origem, a família nuclear constituída através do casamento, bem como a geração presente e membros de famílias reconstituídas. A avaliação desta subcategoria é fundamental, pela possibilidade de existirem múltiplos laços de lealdade com os membros da família alargada que, embora invisíveis, exercem uma influência significativa na estrutura familiar. Além disso, devem ser consideradas as relações especiais e de apoio, que podem persistir independentemente da distância geográfica. Durante a sua avaliação, o enfermeiro deve analisar tanto a quantidade como o tipo de contacto com a família alargada, de forma a compreender a qualidade e quantidade de apoio oferecido.
- <u>Sistemas maiores</u>: geralmente incluem os sistemas de trabalho, e para algumas famílias, podem incluir o sistema de segurança social, proteção de menores, acolhimento familiar, tribunais e clínicas externas. As relações entre as famílias e estes sistemas maiores, podem, por vezes, ser difíceis o que pode ter impacto negativo na família e no seu funcionamento. Apesar de a comunicação sobre os cuidados de saúde entre os diferentes sistemas ser um fator determinante para a satisfação dos utentes, os profissionais de saúde, por vezes, contribuem negativamente para esse processo, ao rotularem as famílias como "não cooperantes", "problemáticas" ou "não aderentes ao regime terapêutico". Nesta subcategoria, outra relação importante a considerar é a utilização da rede informática. Esta abrange redes sociais, fóruns eletrónicos, salas de chat, blogs, mensagens de texto e grupos de discussão. Embora estas plataformas possam ser uma valiosa fonte de informação, validação, empatia, aconselhamento e encorajamento, tendem, na maioria das vezes, a reforçar a situação atual dos membros da família, em vez de estimular mudanças significativas.

O **contexto** inclui cinco subcategorias: etnicidade, raça, classe social, espiritualidade/religião e ambiente.

- <u>Etnicidade</u>: diz respeito à “identidade de grupo” de uma família e surge pela combinação história, raça, classe social e religião. Integra uma comunalidade de diversos processos evidentes e subtis transmitidos pela família ao longo das gerações, geralmente reforçados pela comunidade envolvente. É essencial que os enfermeiros reconheçam a grande diversidade existente tanto dentro como entre os grupos étnicos, bem como a influência significativa desta subcategoria na dinâmica e interação familiar. Na prática clínica, os enfermeiros devem estar sensibilizados para as diferenças nas crenças e valores familiares, evitando a adoção de estereótipos. A este nível, destaca-

se a importância de uma prática de enfermagem baseada na evidência, que privilegie modelos participativos de transferência de conhecimento e de troca de experiências com os grupos étnicos, permitindo que estes se assumam como peritos no seu próprio processo de saúde-doença.

- "Raça": A raça influencia a identificação individual e de grupo, ao mesmo tempo que constrange e fortalece identidades. A raça intersecciona com diversas variáveis mediadoras, tais como a classe social, religião e etnicidade. Atitudes raciais, estereótipos e discriminação são influências poderosas na interação familiar e, se não forem abordadas, podem ter repercussões negativas na relação entre a família e o enfermeiro. Assim, torna-se fundamental que os enfermeiros identifiquem e compreendam a influência da identidade racial nas crenças e comportamentos de saúde adotados pela família.
- Classe social: esta subcategoria desempenha um papel determinante na formação do nível educacional, rendimento e ocupação de uma família, influenciando diretamente o seu acesso a recursos, informação, privilégios e poder subcategoria posição social está associada a um conjunto de valores. Cada posição social carrega consigo um conjunto específico de valores, estilos de vida e comportamentos que afetam não apenas as interações familiares, mas também as práticas de cuidados de saúde. A classe social influência a forma como os indivíduos se definem e são percecionados, o que valorizam, como organizam o seu dia-a-dia e como enfrentam desafios e crises. Embora frequentemente subestimada nas discussões sobre doença, a classe social é um fator fundamental que deve ser considerado pelos profissionais de saúde. Ignorar este contexto pode resultar na não identificação de desigualdades e injustiças que afetam o acesso e a utilização dos serviços de saúde. Assim, os profissionais de saúde devem estar atentos ao impacto da classe social nas crenças, valores e decisões de saúde das famílias, adaptando as intervenções às suas realidades económicas e sociais.
- Espiritualidade e/ou religião: a espiritualidade refere-se a tudo aquilo que confere sentido e propósito à vida de uma pessoa, influenciando a sua forma de estar no mundo e a sua relação com os outros, consigo própria e com o universo. Já a religião diz respeito à afiliação a uma comunidade de fé, que partilha um conjunto de crenças, rituais e valores morais centrados numa entidade transcendente, frequentemente designada por Deus. As crenças e práticas espirituais e/ou religiosas dos membros da família podem influenciar, de forma positiva ou negativa, a maneira como enfrentam e

gerem uma doença ou problema de saúde. Emoções como medo, culpa, raiva, paz e esperança, que impactam a saúde familiar, podem ser moldadas por essas crenças. Embora a espiritualidade e a religião sejam pilares fundamentais da resiliência familiar, com influência direta nos valores, nas práticas de saúde e na socialização, esta dimensão continua a ser frequentemente negligenciada pelos enfermeiros na sua prática clínica.

- Ambiente: Nesta subcategoria estão incluídos diversos aspetos relacionados com a comunidade onde a família está inserida, a localidade e zona onde reside e o próprio ambiente doméstico. Fatores ambientais, como a adequação do espaço e da privacidade, bem como a acessibilidade a escolas, creches, zonas de lazer e transportes públicos, exercem uma influência significativa no funcionamento familiar. Estas questões assumem especial relevância para indivíduos em situações de maior vulnerabilidade, como os idosos, que muitas vezes permanecem em ambientes degradados, mesmo quando estes se tornam perigosos para a sua segurança e bem-estar.

A **Avaliação Desenvolvimental** considera o ciclo de vida familiar, focando-se no estádio de desenvolvimento em que a família se encontra e nas tarefas associadas ao mesmo. Embora o desenvolvimento familiar seja um conceito abrangente, cada família segue um percurso Desenvolvimental único, influenciado tanto pelo seu contexto passado e presente, como pelas suas perspetivas futuras. As autoras do modelo fazem a distinção entre "desenvolvimento familiar" e "ciclo de vida familiar". O "desenvolvimento familiar" refere-se ao percurso singular construído por uma família, moldado por eventos previsíveis e imprevisíveis, como doenças, catástrofes e tendências sociais (ex.: utilização de redes sociais, recessões, desemprego, taxas de natalidade e imigração). Já o "ciclo de vida familiar" remete ao percurso típico experienciado pela maioria das famílias. Esta avaliação tem como objetivo identificar os desafios e as adaptações necessárias em cada fase da vida familiar, como, por exemplo, o impacto de um diagnóstico de doença crónica, e inclui a análise das etapas, tarefas e dos vínculos familiares inerentes a cada fase.

- Etapas: este conceito refere-se às fases pelas quais uma família passa ao longo do seu ciclo de vida, sendo cada uma delas marcada por transições específicas e desafios a enfrentar. Estas etapas não são universalmente aplicáveis, uma vez que as experiências familiares variam amplamente de acordo com fatores culturais, de género e de classe social. A abordagem sistémica ao desenvolvimento familiar requer uma

integração entre as tendências de estabilidade e mudança, reconhecendo que ambas coexistem e são essenciais para o crescimento e adaptação da família. Ao invés de se focar exclusivamente em marcos fixos, como por exemplo o casamento, esta abordagem privilegia as transições e os processos emocionais que acompanham cada fase do ciclo de vida familiar. Desta forma, o enfermeiro deve adotar uma perspetiva flexível, reconhecendo que os vínculos e desafios familiares são moldados por múltiplos fatores e influências, que vão além das simples etapas cronológicas do ciclo de vida.

- Tarefas: referem-se aos desafios e responsabilidades que as famílias enfrentam em cada etapa do seu ciclo de vida, exigindo adaptações e reorganizações para garantir um funcionamento saudável e efetiva diante de novas situações, como o diagnóstico de uma doença crónica.
- Vínculos: estes dizem respeito às conexões emocionais e afetivas entre os membros da família, essenciais para o funcionamento familiar saudável. Estes vínculos são influenciados por fatores como cultura, género, orientação sexual e classe social. A qualidade dos vínculos entre os membros da família pode facilitar ou dificultar a adaptação a desafios, como o diagnóstico de uma doença crónica. A evidência sugere que vínculos fortes e saudáveis promovem maior resiliência familiar, ao passo que vínculos frágeis ou problemáticos podem aumentar o stresse e o risco de disfunção familiar.

A **Avaliação Funcional** incide sobre a forma como a família interage e desempenha as suas funções diárias. O Funcionamento familiar inclui duas subcategorias: o funcionamento instrumental e expressivo.

O **funcionamento instrumental**: este funcionamento familiar diz respeito às atividades habituais, como alimentar-se, administrar medicação, entre outras. Estas atividades tornam-se particularmente significativas nas famílias nas quais há um dos membros diagnosticado com uma doença crónica, pela imposição que a doença tem na frequência e importância destas tarefas para o apoio à gestão dessa doença. A interação entre os aspetos instrumentais e os processos psicossociais na vida das pessoas diagnosticadas constitui um ponto fundamental para os enfermeiros. Em vez de acrescentar novas exigências à já sobrecarregada rotina familiar, os enfermeiros devem procurar integrar as práticas de cuidados de saúde nas rotinas estabelecidas, como nas atividades relacionadas com as refeições e os horários de descanso.

O **funcionamento expressivo**: refere-se à forma como os membros da família comunicam entre si e lidam com os seus sentimentos, pensamentos e crenças. O funcionamento expressivo refere-se à forma como os membros da família comunicam entre si e lidam com os seus sentimentos, pensamentos e crenças. Esta vertente da dinâmica familiar é essencial para compreender como os membros interagem, influenciam-se mutuamente e enfrentam os desafios de saúde, sendo um elemento central na avaliação das relações familiares, especialmente em contextos de doença crónica. O funcionamento expressivo refere-se a nove categorias: a comunicação emocional; a comunicação verbal; comunicação não verbal; a comunicação circular; a resolução de problemas; papéis; influência e poder; crenças; alianças e coligações.

- Comunicação emocional: refere-se à amplitude e à diversidade de emoções ou sentimentos que as famílias expressam, ou que o profissional de saúde observa. De forma geral, as famílias manifestam um vasto leque de emoções, que pode ir da alegria à tristeza ou à raiva. No entanto, famílias que enfrentam dificuldades tendem a exibir padrões mais rígidos e restritos de expressão emocional. O bem-estar subjetivo das pessoas, habitualmente, não está associado ao status socioeconómico, rendimento, níveis de educação, género ou etnia, mas sim a fatores genéticos e influências externas, positivas ou negativas
- Comunicação verbal: centra-se no significado de uma mensagem oral (ou escrita) entre os envolvidos na interação, ou seja, o foco está no sentido das palavras em função da relação entre as partes. A comunicação verbal direta implica que a mensagem seja transmitida de forma clara ao destinatário pretendido, sem distorções. Por outro lado, na comunicação indireta, as ideias são transmitidas de forma menos explícita, tornando a mensagem mais ambígua ou difusa.
- Comunicação não verbal: centra-se nas várias mensagens não verbais e paraverbais transmitidas pelos membros da família, como postura corporal, contacto visual, toque, gestos e expressões faciais. O espaço pessoal, ou proximidade entre os membros, também é relevante. A comunicação paraverbal inclui a entoação, o tom de voz, ritmo de discurso. É importante que os enfermeiros reconheçam que a comunicação não verbal é fortemente influenciada pela cultura e que explorem o seu significado, sobretudo quando há inconsistências com a comunicação verbal.
- Comunicação circular: refere-se à troca recíproca de mensagens entre indivíduos, onde cada um exerce influência sobre o comportamento do outro. Um exemplo típico

é a crítica entre familiares, em que cada membro tende a perceber o problema como exclusivo do outro, sem reconhecer a sua própria contribuição para a situação. Este padrão é essencial para compreender as interações em díades, pois ilustra como o comportamento de uma pessoa afeta diretamente o comportamento da outra. Embora útil numa perspetiva sistémica, promovendo uma visão colaborativa, este tipo de comunicação pode apresentar limitações, como desviar a responsabilidade individual. É crucial que os enfermeiros reconheçam a sua interdependência com a família, bem como a influência mútua dos contextos onde ambos estão inseridos.

- Resolução de problemas: refere-se à capacidade da família de resolver de forma efetiva os seus próprios desafios. Esta competência é fortemente influenciada pelas crenças da família sobre as suas capacidades e sucessos passados. Assume-se como determinante, no processo de resolução de problemas, a capacidade da família de identificar as dificuldades, acreditar que tem alguma influência sobre estas e encontrar soluções adequadas. O enfermeiro deve reconhecer as limitações da família nestes aspetos, promovendo o seu envolvimento ativo em todo o processo, incentivando uma abordagem colaborativa e facilitando o desenvolvimento de competências para lidar com os desafios identificados.
- Papéis: Os papéis desempenhados pelos membros da família, sejam eles formais ou informais, são moldados por fatores culturais, sociais e normas familiares, e não são estáticos, evoluindo com o tempo e as interações. A avaliação dos papéis é essencial para compreender o funcionamento familiar, uma vez que conflitos ou cooperação nos papéis podem impactar significativamente a dinâmica familiar. Os enfermeiros devem considerar tanto os papéis formais, como os de mãe ou pai, quanto os informais, como comportamentos únicos atribuídos a certos membros da família. Esta compreensão permite identificar se, ou quais os papéis que precisam de ser ajustados para melhorar o bem-estar familiar.
- Influência e poder: referem-se ao comportamento utilizado por uma pessoa para afetar o comportamento utilizado por uma pessoa para afetar o comportamento. O poder diz respeito a posições hierárquicas e igualitárias nas relações. Numa relação hierárquica, uma pessoa pode estar numa posição superior ou inferior na relação e pode ser dominante num contexto e subordinada noutro. Numa relação igualitária, há igualdade na relação - numa relação mais igualitária, há uma negociação entre as necessidades, objetivos e desejos individuais. A influência ou poder psicológico refere-se à utilização

da comunicação e dos sentimentos para influenciar o comportamento. Por outro lado, a influência, poder ou controlo instrumental refere-se à utilização de objetos ou privilégios (por exemplo, dinheiro, utilizar o computado. Um enfermeiro que não reconheça as dinâmicas de poder existentes entre os membros da família, relacionadas com papéis, género, economia ou classe social, pode, sem intenção, incentivar os membros em posições de menor poder a aceitar objetivos que limitam a sua autonomia e restringem as suas escolhas. É crucial que o enfermeiro discuta com os familiares as áreas de poder e influência, como a tomada de decisões sobre a gestão da doença, tarefas domésticas, entre outros. A forma como um membro da família tenta influenciar o outro é determinante para a relação e pode afetar a gestão da doença. Estudos demonstram que estratégias de controlo positivo, como o encorajamento, têm um impacto positivo na adesão a regimes terapêuticos, como no caso da diabetes. Portanto, a tomada de decisões colaborativa é essencial na gestão de doenças crónicas, e o enfermeiro deve promover a partilha de responsabilidades entre todos os membros da família.

- Crenças: As crenças referem-se a atitudes, premissas, valores e suposições fundamentais mantidos pelas famílias e seus membros. As famílias desenvolvem um ecossistema de crenças influenciadas pelos contextos de interação, sociais e culturais. Quando surge uma doença, essas crenças sobre saúde podem ser desafiadas, ameaçadas ou reforçadas. Durante períodos de doença, as crenças das pessoas diagnosticadas, dos membros da família ou até dos próprios enfermeiros podem ser vistas como limitadoras ou facilitadoras. Crenças limitadoras aumentam o sofrimento e reduzem as opções de solução, enquanto crenças facilitadoras podem atenuar o sofrimento e ampliar as opções de gestão da doença. As crenças mais relevantes para a prática clínica do enfermeiro incluem as relacionadas com a etiologia, diagnóstico, prognóstico, cura, tratamento, espiritualidade, controlo, papel dos membros da família e dos profissionais de saúde.
- Alianças e coligações: referem-se aos relacionamentos e dinâmicas de poder que se estabelecem dentro da família. As alianças são uniões estáveis e emocionais entre os membros da família, caracterizadas por vínculos duradouros e de apoio mútuo. As coligações, por sua vez, consistem em alianças entre membros da família que podem ter um impacto positivo ou negativo. Coligações positivas surgem quando os familiares se unem em prol de um objetivo comum, como apoiar um membro na adoção de

comportamentos mais saudáveis. Por outro lado, coligações negativas manifestam-se quando dois membros da família se alinham em oposição ou exclusão de um terceiro. É crucial que os enfermeiros compreendam a direccionalidade, equilíbrio e intensidade das relações entre os membros da família, bem como entre as famílias e os profissionais de saúde. Este entendimento é essencial para identificar dinâmicas que promovam o equilíbrio e o apoio familiar, evitando a perpetuação de tensões e conflitos. Quando se lida com o diagnóstico de uma doença, é fundamental avaliar a perceção da família em relação à doença. Um exemplo comum do que pode ocorrer inadvertidamente é a família interpretar a doença de um membro como “problema dele”, em vez de a encarar como um "desafio comum". Esta perceção cria uma divisão entre a pessoa diagnosticada paciente, o seu parceiro saudável e os outros membros da família. Ao introduzir o conceito de “nosso desafio”, o enfermeiro pode facilitar uma reflexão familiar sobre crenças culturais e multigeracionais, relacionadas com os direitos e responsabilidades dos familiares doentes e saudáveis.

O CFAM, é um modelo de avaliação familiar abrangente e inclusivo, que fornece uma estrutura que permite reunir todas as informações relevantes numa avaliação integrada. O enfermeiro, através da utilização de três categorias principais deste modelo teórico (estrutural, desenvolvimental e funcional), obtém uma avaliação das forças, recursos, problemas e/ou sofrimentos da família. Após esta avaliação das áreas a intervir na família, as autoras sugerem o modelo de intervenção para as mesmas.

O **Modelo de Intervenção Familiar de *Calgary* (CFIM)**, tem como objetivo melhorar o funcionamento familiar, atendendo às necessidades de saúde dos seus membros. As intervenções podem ser direcionadas tanto para a pessoa individualmente como para o sistema familiar como um todo. Este modelo, trata-se de ferramenta dinâmica que auxilia os enfermeiros, em colaboração com a família, a identificar a principal área que necessita de intervenção e determinar as estratégias mais efetivas para promover a saúde e o bem-estar dos membros familiares. Ao basear-se nas forças e resiliência da família, o CFIM rompe com a prática tradicional focada exclusivamente nos défices e disfunções, incentivando uma abordagem mais positiva e colaborativa. Assim, o modelo enfatiza a importância de alterar a perceção dos membros da família em relação à sua condição de saúde, promovendo uma transformação profunda nos domínios cognitivo, afetivo e comportamental. Apesar das intervenções poderem incidir sobre diferentes aspetos do funcionamento familiar, a mudança

mais relevante e sustentável verifica-se nas crenças da família (cognição), uma vez que estas orientam a forma como a família lida com a situação e responde aos desafios.

Os enfermeiros, enquanto facilitadores da mudança, devem oferecer intervenções às famílias estabelecendo uma relação de confiança e colaboração. O seu papel não é impor ou exigir alterações no comportamento familiar, mas sim o de encorajar e apoiar, através de uma parceria efetiva e de forma colaborativa. As intervenções são por esta perspetiva desenvolvidas com a família, valorizando o diálogo e a troca de perspetivas entre o enfermeiro e as experiências vividas pelas pessoas envolvidas. Esta promoção da parceria entre os enfermeiros e a família, capacita os seus membros para identificar desafios e encontrar soluções, além de aumentar a sua recetividade às intervenções propostas.

O CFIM categoriza as intervenções em três áreas principais: educação e informação, suporte emocional e resolução de problemas, que proporciona apenas uma estrutura para alinhar as intervenções de enfermagem com as áreas de maior necessidade no funcionamento familiar. Assim, fica excluída a possibilidade de uma abordagem rígida, generalista ou padronizada com as famílias. Assim, as principais características das intervenções incluem:

- Educação e Informação: foca-se na partilha de conhecimento e esclarecimento de dúvidas sobre a condição de saúde, tratamentos ou cuidados necessários. As intervenções neste domínio objetivam aumentar a compreensão da família sobre a doença, melhorar as suas competências para lidar com a gestão da mesma e promover comportamentos de saúde. Estas informações devem ser claras e adaptadas ao nível de literacia de saúde da família, para que os membros possam tomar decisões informadas e contribuírem ativamente para o plano de cuidados. A educação é, assim, um elemento chave que ajuda a reduzir a ansiedade e incertezas, promovendo uma participação mais consciente e efetivas no processo de gestão da doença.
- Suporte emocional: é um componente essencial da intervenção, cujo objetivo é assegurar que os membros da família consigam lidar com o impacto emocional resultante de conviver com um familiar diagnosticado com uma condição crónica ou grave. Este modelo enfatiza a importância das emoções, como o medo, a ansiedade e a frustração, na medida em que estas podem influenciar diretamente o envolvimento das famílias nos cuidados prestados. Assim, a intervenção de enfermagem deve criar um ambiente de apoio no qual os membros da família se sintam encorajados a expressar abertamente e de forma sincera as suas preocupações, sentimentos e

receios, promovendo, desta forma, uma atmosfera de segurança e de reforço da sua resiliência emocional.

- Resolução de problemas: esta área da intervenção centra-se na capacidade da família para identificar e gerir os desafios associados à doença. O enfermeiro atua como facilitador, encorajando a família a desenvolver soluções efetivas e colaborativas para os problemas, seja em termos de cuidados diários, desafios emocionais ou logísticos. A família é incentivada a refletir sobre as suas competências, limitações e a explorar estratégias adaptativas para melhorar o funcionamento familiar e a gestão da doença

No contexto da diabetes, a aplicação dos Modelos de Avaliação e Intervenção Familiar de *Calgary* na prática clínica, possibilita o desenvolvimento de intervenções personalizadas, fundamentadas numa avaliação holística que visa promover mudanças cognitivas, emocionais e comportamentais. Estas intervenções não só fortalecem o suporte familiar, como também otimizam a autogestão da diabetes, garantindo uma abordagem mais efetiva e sustentável aos desafios inerentes à diabetes.

Ao proporcionar uma compreensão abrangente das interações familiares da pessoa com diabetes, este modelo permite identificar necessidades educativas e fatores físicos, emocionais, sociais e económicos que influenciam a dinâmica familiar. A implementação de estratégias ajustadas a essas especificidades promove o bem-estar de todos os membros da família, refletindo-se diretamente na gestão da diabetes e na melhoria dos resultados em saúde (Wright & Leahey, 2013).

As Intervenções que têm por base este modelo oferecem aos enfermeiros uma abordagem flexível e fundamentada na evidência, assegurando que as necessidades específicas das pessoas sejam supridas de forma personalizada (Wright & Leahey, 2013). Este enquadramento têm o potencial de otimizar a comunicação, melhorar a resolução de conflitos familiares e o fortalecimento do apoio mútuo, que são elementos essenciais no contexto das doenças crónicas. Assim, contribui para a eficácia das estratégias de autogestão e para a sustentabilidade dos comportamentos de saúde, reforçando o papel central da família no suporte à pessoa diagnosticada (American Diabetes Association, 2023; McEwen et al., 2019; Pamungkas & Chamroonsawasdi, 2020; Pamungkas et al., 2017).

Reconhecendo o papel crucial da família, é fundamental que enfermeiros e investigadores aprofundem o conhecimento sobre os desafios das intervenções educativas direcionadas à pessoa com diabetes e à sua família, bem como sobre os fatores que influenciam a sua implementação e eficácia (Wright & Leahey, 2013).

A adoção dos Modelos de Avaliação e Intervenção Familiar de *Calgary* representa uma transformação significativa na abordagem dos cuidados de enfermagem, posicionando a família como elemento central. Este modelo não se limita a identificar e intervir nas dinâmicas familiares; ele amplia o papel do enfermeiro, transformando-o em um facilitador de mudanças que vão além da pessoa diagnosticada, abrangendo toda a unidade familiar (Wright & Leahey, 2013).

A integração deste modelo na prática clínica permite superar abordagens tradicionais centradas exclusivamente na pessoa, promovendo a autogestão da doença e o suporte emocional e funcional entre os membros da família. Ao capacitar os enfermeiros para trabalhar de forma colaborativa com as famílias, os Modelos de *Calgary* contribuem significativamente para melhores resultados em saúde, a sustentabilidade dos comportamentos de autocuidado e a melhoria da qualidade de vida de todos os envolvidos (Bennich et al., 2019; Bennich et al., 2017; Shajani & Snell, 2019). Este enquadramento teórico oferece uma base sólida para uma prática de enfermagem mais inclusiva e efetiva, desafiando os profissionais a expandirem continuamente as suas competências e a adaptarem as suas intervenções às especificidades únicas de cada família. Além de enriquecer a prática atual, o modelo abre caminho para novas abordagens na investigação e na educação em saúde, promovendo uma visão verdadeiramente integrada da gestão de doenças crónicas como a diabetes.

CAPÍTULO III. IDENTIFICAÇÃO DA EVIDÊNCIA / ANÁLISE DA PRÁTICA CORRENTE E CONTEXTO ATUAL

Este capítulo aborda duas das fases do Modelo das Intervenções Complexas da *Medical Research Council* (MRC): a identificação da evidência existente e a análise da prática corrente e do contexto atual (Bleijenberg et al., 2018; Craig et al., 2008; Richards & Hallberg, 2015). Estas etapas são fundamentais para construir uma base sólida que sustente o desenvolvimento de intervenções efetivas, ajustadas às necessidades específicas da pessoa com diabetes e da sua família.

Assim, neste capítulo, são apresentados dois artigos que complementam e sustentam o enquadramento teórico dos capítulos anteriores. O primeiro artigo corresponde a uma revisão sistemática das características psicométricas dos instrumentos utilizados na avaliação do envolvimento familiar no contexto do adulto com diabetes, identificando ferramentas robustas para a avaliação dessa dinâmica. O segundo artigo consiste numa revisão *umbrella* que sintetiza a evidência disponível sobre a efetividade de intervenções centradas na família do adulto com diabetes, destacando estratégias e os seus impactos nos resultados em saúde.

Estes estudos são complementares e oferecem um suporte empírico valioso para as fases subsequentes da investigação, permitindo, não só, consolidar as bases teóricas, mas também orientar o desenvolvimento da intervenção psicoeducativa direcionadas à promoção de uma gestão mais efetiva e holística da diabetes.

ARTIGO: *Diabetes Mellitus Family Assessment Instruments: A Systematic Review of Measurement Properties* – Artigo publicado na ***International Journal of Environmental Research and Public Health*** (2023)

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Systematic Review

Diabetes Mellitus Family Assessment Instruments: A Systematic Review of Measurement Properties

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Abstract: Although many instruments are used to assess the families of people with diabetes, their measurement properties have not been systematically reviewed. We aimed to identify and evaluate the psychometric properties of the instruments used to assess family functioning in adults with diabetes. Methods: A systematic literature review, according to the JBI systematic reviews of measurement properties, was conducted using different databases, including gray literature. PROSPERO registration number: CRD42021239733. Two independent reviewers searched, screened, and assessed the risk of bias among the articles according to the COSMIN methodology. The quality of each included instrument was assessed using the updated criteria for good measurement properties. Results: Eighty-one studies were included, and thirty-one eligible instruments were identified. The psychometric properties frequently assessed were structural validity, internal consistency, and construct validity. Conclusions: Although 31 instruments were included, none of their psychometric properties were scored as "very good". From the instruments scored as adequate on development and content validity, five stood out for their quality appraisal.. The development of new instruments is not recommended. More studies should be conducted on the existing instruments to assess the less commonly evaluated psychometric properties. Using valid instruments to develop and evaluate interventions is essential to promote health literacy and the effectiveness of diabetes management.

Keywords: diabetes mellitus; family; health literacy; nursing; psychometrics; systematic review

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1. Introduction

Diabetes Mellitus, from now on referred to as diabetes, is considered to be a global health emergency, affecting approximately 537 million adults [1]. Due to its strong impact at different levels, including personal, social, and health systems, diabetes is presently in the global political agendas, and it is imperative to slow down its epidemic curves and risk factors.

The diagnosis of a chronic disease, such as diabetes, is a critical event with a psychological impact that affects the patient's personality development and psychosocial functioning, as well as the health of their family members [2].

Being diagnosed with diabetes requires changes in their lifestyle and the integration of complex, long-term, daily self-management routines. In addition, the family, as the primary source of health information, is affected, and this determines how people with diabetes accept the challenges and demands that diabetes imposes [3,4].

1.

Despite their health literacy level and diabetes-specific knowledge, the patient and their family are responsible for disease management [5]. Therefore, family is a crucial source of social support in diabetes day-to-day care.

The importance of social support, namely, familial involvement in diabetes management, has been highlighted in the literature as a determining factor for the patient's well-being and the success of the different approaches that have been developed [6,7].

Social support can be defined as the existence or availability of people who can help and care when they are needed [8], and it is strengthened by the social bonds between people. This support can be provided by direct family members, peers, friends, neighbors, co-workers, or contacts that are established through social networks [9], and it has led to improvements in the management of diabetes [10,11].

Diabetes requires multidimensional care, and the family is considered to be a care unit [12].

However, it is important to be aware of the numerous changes that have occurred in the concept of family in recent decades. Family is not restricted to blood ties or a legal definition, in contrast, "family is who they say they are" [13] (p. 55).

From the moment of diagnosis, it is essential to care not only for the patient, but also for the family, identifying and understanding the psychosocial factors in diabetes management, including family functioning.

Family functioning is defined as a multidimensional construct, and it comprises two dimensions [14]: family competence (the family structure and capacity to adapt to changes) and family style (the style and quality of family interaction). According to Andrade et al. [15], family functioning can be defined as how members cope with difficulties, conflict situations, means of survival, and role distribution.

In people with diabetes, family functioning is one of the main factors that affects the patient's quality of life [16], and it is directly associated with the perception that people with diabetes have of their family members' involvement and support in disease management [17].

Person-centered approaches for people with diabetes allow us to identify the individual and clinical characteristics relevant to the disease, the importance of which is undeniable. However, studies on diabetes and its complications [1,6] have exposed the fragility of these individualized approaches, and there is an emerging need to identify new strategies that are meant to be more effective.

It is essential to empower and promote health literacy, not only people with diabetes, but their families, involving them actively and intentionally in the behavioral changes that the disease requires, which are aiming at the prevention and reduction of complications, as well as assuring an excellent quality of life [11,18].

Studies developed on the family involvement in diabetes are mainly focused on children and/or adolescents with type 1 diabetes and their caregivers, usually the parents. Studies on the families of adult people with diabetes are scarce in the literature [19].

Gaps in the literature are evident in terms of the evaluation and involvement of the family in the process of managing diabetes when the patient is an adult.

Several instruments have been developed and used to assess family functioning, however, they are not specific to families of people with diabetes [19]. Nurses should be encouraged to learn more about family assessment instruments and to make the decision to use one instrument in preference to another in their nursing practice according to the construct of interest and the psychometric properties of each instrument. This will allow researchers to develop interventions adapted to the specifics of each patient and their family, as well as to their context, with a consequential improvement in the health outcomes, namely, health literacy.

A preliminary analysis of the literature allowed us to conduct a systematic review of diabetes-specific family assessment instruments research dating to between 1982 and 2010, which included participants with diabetes of different ages (including children and adolescents) and their families. In this study, the authors consider the importance

of professionals deepening their knowledge about the different instruments of family assessment (diabetes specific and generic) and evaluating their effectiveness according to the research questions and objectives of clinical practice [19].

In the preliminary search in the JBI Database of systematic reviews and implementations reports, the Cochrane database of systematic reviews, CINAHL (via EBSCO), the COnsensus-based Standards for the selection of health Measurement INstruments (COSMIN) Database of Systematic Reviews, MEDLINE (via PubMED), Scielo and Prospero, we did not find other types of literature reviews (published or to be developed) in the study area.

Although family assessment instruments have been developed and used on the families of people with diabetes, the assessment of the methodological quality of the studies and the measurement properties have not been reviewed.

This review was conducted to identify and critically evaluate the psychometric properties of the different instruments used to assess family functioning of the families of people with diabetes.

2. Methods

The systematic review was developed according to the JBI systematic reviews of measurement properties [20] to answer the following review question: "What are the instruments used to assess family functioning in families with people with diabetes, and what are their psychometric properties?".

The study protocol was registered in PROSPERO (registration number: CRD42021239733). The review team conducted a thorough analysis of the preliminary searches (prior to the protocol development), and they made a few changes to the protocol before conducting the study selection, however, it is important to point out that the initial focus was maintained.

2.1. Search Strategy

A systematic review was conducted using databases and scientific repositories, continuing the study developed by Song et al. [19], and it was limited to studies from 1 January 2010 to 8 June 2021.

According to the JBI recommendations, the search strategy included an initial search for studies published in the PubMed, CINAHL, and Scielo databases using keywords such as "diabetes" OR "diabetic" AND "family" OR "families", the aim of which was to identify the indexed and free text terms most frequently used in this area of study within titles and abstracts of the studies.

A second search was conducted with the indexed search terms and keywords, which was adapted and individualized to the following electronic databases: MEDLINE®, CINAHL®, Scopus®, Cochrane Library, SciELO—Scientific Electronic Library Online, PsycINFO (access via EBSCOhost Web) and JBI Evidence Synthesis.

Regarding the gray literature, it was mapped using the databases: RCAAP (Scientific Open Access Repository of Portugal) and OpenGrey. The search strategy used for MEDLINE® is provided in Supplementary Material File S1.

In addition, a manual search was performed with the Google Scholar web search using the keywords (diabetes AND "family assessment instruments" OR "social support"). The studies identified were screened manually to check all of the references and to identify the potentially relevant studies. When the studies' methodology did not properly describe the instruments, the respective validation studies were identified as a source of additional psychometric information, regardless of the year of publication [21–32].

The search was performed by two independent reviewers, and it was supported by a librarian.

2.2. Study Eligibility Criteria

The studies were eligible if they included any instrument that was developed, tested, or used to assess one or more attributes of family functioning of the families of adult people

with diabetes, including published and unpublished primary studies, after 2010, despite the country or setting.

As a source of additional information on the psychometric properties, the development and validation studies of the identified instruments were included regardless of the year of publication.

Studies published in English, Portuguese, Spanish and French were included based on the level of linguistic proficiency of the reviewers, ensuring greater rigor in the selection of evidence and data extraction.

We excluded studies whose methodology was not adequately described and those that did not provide additional information about the instruments' psychometric properties. Studies were also excluded if the population was under the age of 18 years. Systematic reviews and qualitative studies were also excluded.

2.3. Study Selection

This process was performed by two reviewers, and it is presented and organized in a PRISMA flow diagram [33].

The articles were screened for inclusion using the Endnote X9® Software reference management software (Clarivate Analytics, Philadelphia, PA, USA), and duplicate references were identified and removed. Two authors independently screened the titles and abstracts. The same two authors assessed the potentially relevant full-text information. Disagreements between the two reviewers at any stage of this process were resolved by coming to a consensus or through performing an analysis and having a discussion with a third reviewer.

2.4. Assessment of Methodological Quality and Assessment of Measurement Properties

The methodological quality of the studies was assessed through the COSMIN guideline for systematic reviews, which was developed specifically for patient-reported outcomes measures (PROMs), which can also be used in other types of measurement instruments [34].

The systematic review only included studies satisfying the criteria of the methodological quality assigned to each study using the COSMIN Risk of Bias checklist [34].

The ten boxes of the COSMIN include: (1) instrument development; (2) content validity; (3) structural validity; (4) internal consistency; (5) cross-cultural validity; (6) reliability; (7) measurement error; (8) criterion validity; (9) hypothesis testing; (10) responsiveness. Each standard was rated on a four-point rating system as 'very good', 'adequate', 'doubtful', or 'inadequate'. The overall quality rating for each study was determined by taking the lowest rating on an item of any box [34–36].

The content validity, which is considered to be the most important measurement property, was evaluated [36].

To assess the quality of each instrument regarding the measurement property, the updated criteria for good measurement properties was applied [34].

The results were rated as sufficient (+), insufficient (−), or indeterminate (?), and the principle of "the worst score counts" was applied.

Using the COSMIN methodology, we defined the hypotheses in advance to evaluate the results of studies on construct validity:

- Correlations with instruments used to measure the same construct should be >0.50;
- Correlations with instruments used to measure related constructs should be in the range of 0.30–0.50.

Two reviewers performed each step-in assessment of the methodological quality, and the results were obtained by coming to a consensus.

2.5. Evidence Synthesis

The evidence synthesis was conducted according to the COSMIN methodology [34–36]. The key characteristics of each instrument tested, the COSMIN Risk of Bias checklist results for the instrument development, the content validity, the others measurement

properties, and the results of each study on each measurement property have been rated and summarized in tables.

Relevant information from all of the included studies is described in Supplementary Material File S2. The summary of the principal results on the measurement properties of each instrument described in the different studies is reported in Supplementary Material File S3.

3. Results

3.1. Studies Selection

The search strategy identified 1031 studies. After removing the duplicates, 591 articles were screened by the relevance of their titles and abstracts. The remaining 66 full-text articles were assessed for eligibility, and seven of them were excluded for different reasons. As an additional source of psychometric information, 22 additional articles were identified through reference screening. A total of 81 articles were included in this systematic review, and 31 family assessment instruments were identified (Figure 1).

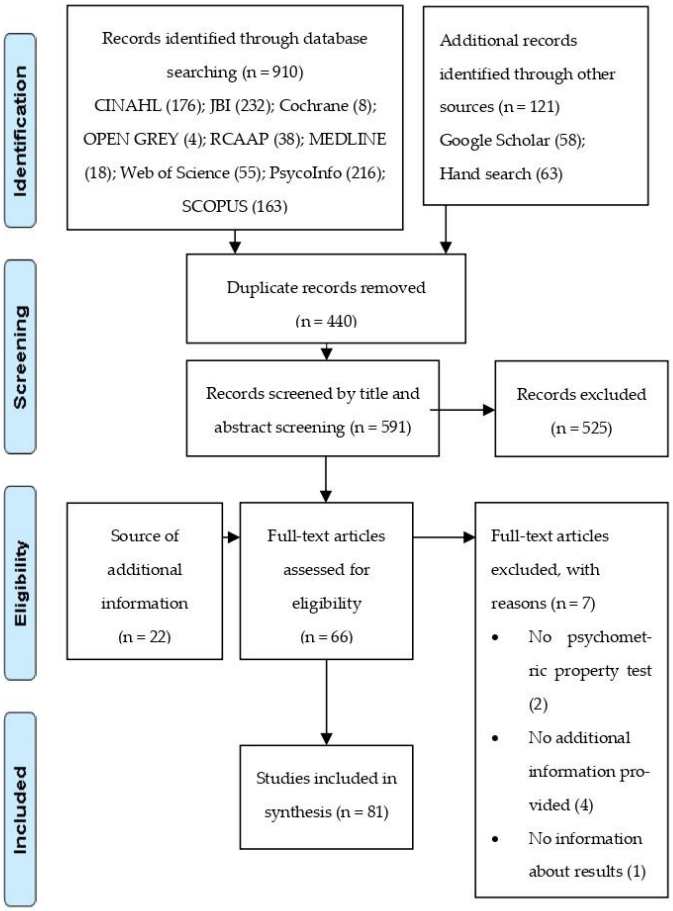

Figure 1. PRISMA flow chart of study selection.

3.2. Study Characteristics

In this systematic review, 39 studies were conducted in the USA. The remaining 42 studies were conducted in 24 different countries.

The study design that was mainly used was cross-sectional. The sample size ranged from 48 to 8596 participants. The community setting was reported in 62 studies. Other settings included hospitals and diabetes centers.

The majority of the studies did not describe the concept of family. Eight studies focused on the concept of family in terms of the patients' marital status, blood ties, close relatives, or living with patients, and another eight studies had a broad approach to the concept of family.

In the Supplementary Material, File S2 presents the relevant information of each included study, and File S3 summarizes the results of the measurement properties analysis of each instrument described in the different studies that were included.

3.3. Instruments Characteristics

The review identified 31 instruments; 15 of them were specific instruments used to assess the families of people with diabetes. Table 1 summarizes the information for each instrument included (diabetes-specific and generic ones).

Table 1. Summary information of each instrument (Diabetes Mellitus specific and generic) in alphabetical order.

Instrument	References	Type of Measure	Target Population (According to the Validation Study)	Construct(s)	Subscales, Number of Items	Response Options	Theoretical Background
Diabetes Mellitus-Specific Instruments							
Diabetes Caregiver Activity and Support Scale (D-CASS)	[37]	Patient interview	Family. Target family caregivers of persons with T2DM	Caregiver perceptions of difficulty with activities and supportive behaviors specifically while providing care for a person with T2DM	11 items Unidimensional scale	7-point Likert scale	Literature Review
Diabetes Care Profile (DCP)	[7,38–42]	Self-reported	Patients/Target patients with diabetes	Social and psychological factors related to diabetes and its treatment	234 items with 16 scales (control problems, social and personal factors, positive attitude, negative attitude, self-care ability, importance of care, self-care adherence, diet adherence, medical barriers, exercise barriers, monitoring barriers, understanding management practice, long-term care benefits, support needs, support, and support attitude)	Filling in the blanks with the correct answers or by choosing the single best answer	Diabetes Educational Profile and Health Belief Model
Diabetes Family Behavior Checklist (DFBC)	[31,43–48]	Self-reported	Patient/family member dyad. Target insulin-dependent Diabetes Mellitus (IDDM) patients and families	Supportive and non-supportive family behaviors specific to the diabetes self-care regimen (drug therapy, blood glucose measurement, exercise, and diet)	16 items that can be divided into 2 subscales for analysis (positive feedback—9 questions; negative feedback—7 questions)	5-point Likert scale	Literature review including information from people diagnosed with diabetes and a health professional who is familiar with the disease
Diabetes Family Behavior Checklist-II (DFBC-II)	[29,49–52]	Self-reported	Patients/ family member dyad. Target patients with type 2 diabetes	Family member's actions toward the person with type II diabetes (medication taking, glucose testing, exercise, and diet)	DFBC-II version for a partner or significant other: 17 items that can be divided into 2 subscales for analysis (positive feedback—9 questions; negative feedback—7 questions) open-ended item DFBC-II version for diagnosed person: 17 items and a new section designed to assess 17 family behaviors	5-point Likert scale 7-point Likert scale (DFBC-II section for diagnosed person)	Literature Review and Diabetes Family Behavior Checklist (DFBC)
Diabetes Family Support and Conflict scale (DFSC)	[53,54]	Self-reported	Patients. Target patients with type 2 DM	Diabetes-related family support and conflict	10 items including 2 subscales (supportive—6 items; unsupportive—4 items)	4-point Likert scale	Literature review and information from healthcare professionals and patients with diabetes
Diabetes Mellitus 2 treatment adherence scale version III (EATDM-III)	[55]	Self-reported	Patients. Target patients with type 2 diabetes	Treatment adherence	30 items including 6 subscales (physical exercise, family support, medical control and treatment, community support and organization, diet, and information)	5-point Likert scale	Literature Review and subjective reports from providers and patients

Table 1. *Cont.*

Instrument	References	Type of Measure	Target Population (According to the Validation Study)	Construct(s)	Subscales, Number of Items	Response Options	Theoretical Background
Diabetes Support Scale (DSS)	[28,42]	Self-reported	Patients. Target patients with diabetes (type 1 and 2)	Diabetes social support	12 items including 3 subscales (emotional support, advice, information)	7-point Likert scale	Literature Review and rational-theoretical approach
Empowerment questionnaire	[46]	Self-reported	Patients. Target patients with type 2 diabetes	Empowerment of type 2 diabetes patients (based on self-managed dietary/exercise behaviors, psychological impact, and family support)	31 items including 5 scales (self-managed dietary behaviors, self-managed exercise behaviors, psychological impact of diabetes, and positive and negative feedback in patient-family communication) and 13 questions on background	5-point Likert scale Filling in the blanks with the correct answers	Literature review and Japanese-language versions of the Appraisal of Diabetes Scale and Diabetes Family Behavior Checklist
Family-Carer Diabetes Management Self-Efficacy Scale (F-DMSES)	[56]	Self-reported	Families. Target family of patients with type 2 diabetes	Family-caretaker diabetes management and self-efficacy.	14 items including 4 subscales (General diet and blood glucose monitoring, medication and complication, diet in different situations, weight control, and physical activities)	5-point Likert scale	Diabetes Management Self-Efficacy Scale (DMSES)
Family and Friend Involvement in Adults' Diabetes (FIAD)	[57,58]	Self-reported	Patients. Target patients with type 2 diabetes	Family/friend involvement	16 items including 2 subscales (helpful involvement, harmful involvement)	5-point Likert scale	Literature review, cognitive interviews, and expert input
Family Support Scale adapted for African American women with type 2 Diabetes Mellitus (FSS-AA)	[59]	Self-reported	Patients. Target women with uncontrolled T2DM	Diabetes-specific social support	16 items including 3 subscales (parent and spouse/partner support, community and medical support, extended family and friends support)	5-point Likert scale	Original Dunst Family Support Scale (FSS)
Helping for Health Inventory: Couples Version (HHI-C)	[60]	Patient interview	Patients. Target patients with type 2 diabetes	"Miscarried helping" in couples	15 items including 3 subscales (Conflict/Blame, Partner Investment, Resistance)	5-point Likert scale	Theoretical concept of "miscarried helping" and "Helping for Health Inventory" scale
Multidimensional Diabetes Questionnaire (MDQ)	[25,61]	Self-reported	Patients. Target patients with non-insulin-dependent diabetes	Patients' psychosocial adjustment to diabetes	41 items grouped into three sections: Section I: 16 items including 3 scales (perceived interference caused by diabetes to daily activities, work, and social and recreational activities; perceived severity of diabetes; perceived diabetes-related social support from a significant other, family, friends, and health professionals) Section II 12 items including 2 scales (positive reinforcing behaviors and specific form of non-supportive behaviors) Section III 13 items including 2 scales (self-efficacy expectancies and outcome expectancies)	Section I and II: 7-point Likert scale Section III: rated from 0 to 100	Literature Review and Social Learning Theory
Social Support Scale for Self-care in Middle-aged Patients (S4-MAD)	[62]	Patient interview	Patients. Target patients with diabetes	Social support for self-care in diabetic patients	30 items including 5 subscales (nutrition, physical activity, self-monitoring of blood glucose, foot care, and smoking)	5-point Likert scale	Literature review
Unsupportive social interaction scale (USIS)	[63]	Patient interview	Patients. Target patients with diabetes	Unsupportive social interactions	15 items including 2 scales (interference and insensitivity)	5-point Likert scale	Literature review and information from patients with diabetes
Generic instruments							
Brief Family Assessment Measure-Brief (Brief FAM-III)	[64,65]	Self-reported	Patients. Target patients with type 2 diabetes	Family's strengths and weaknesses	42 items including 3 scales (general, dyadic relationships, and self-rating)	4-point Likert scale	Model of Family Functioning
Chronic Illness Resources Survey (CIRS)	[66,67]	Self-reported	Patients. Target post-menopausal women with type 2 diabetes	Multilevel support resources from proximal support (e.g., family and friends) to more distal factors (e.g., neighborhood or community)	22 items including 9 subscales (personal; family and friends; physician/health care team; neighborhood/community; organizations; work; media and policy; dietary and physical activity)	6-point Likert scale	Multilevel, Social–Ecological Model
Family Adaptability and Cohesion Evaluation Scale (FACES IV)	[68–70]	Self-reported	Adults. Target Students and nonclinical family	Family functioning (family adaptability and cohesion)	42 items including 2 Balanced scales (cohesion and flexibility) and 4 Unbalanced scales (disengaged, enmeshed chaos, and rigid)	5-point Likert scale	Circumplex model and family therapists from American Association for Marriage and Family Therapy
Family APGAR Index	[15,30,32,71–74]	Self-reported	Clinical group(patients)/nonclinical group dyad. Target "normal" families' members and psychiatric outpatients	Global family function	5-item questionnaire that is designed to test five areas of family function (adaptation; partnership; growth, affection, and resolve) Unidimensional scale	3-point Likert scale	Literature review

Table 1. *Cont.*

Instrument	References	Type of Measure	Target Population (According to the Validation Study)	Construct(s)	Subscales, Number of Items	Response Options	Theoretical Background
Family Assessment Device (FAD)	[16,27,75–77]	Self-reported	Students and patient's family. Target psychology students and a group of patient's family	Family functioning	53 items (currently is in use a 60-items version) including 7 scales (general functioning, communication, affective involvement, roles, problem solving, affective responsiveness, behavior control)	4-point Likert scale	McMaster Model of Family Functioning (MMFF)
Family Emotional Involvement and Criticism Scale (FEICS)	[24,58,78]	Self-reported	Patients. Target patients receiving primary medical care	Perceived family criticism and emotional involvement	2 subscales (Family's Perceived Criticism—7 items; Intensity of Emotional Involvement—7 items)	5-point Likert scale	Expressed Emotion (EE) theory
Family Function Questionnaire (FFQ)	[17,79]	Self-reported	Families. Target caregivers of psychiatric patients	Perceived family function	24 items including 3 subscales (problem-solving, communication, and personal goal)	4-point Likert scale	Literature Review and Cognitive-behavioral Family Treatment
Family Functioning Style Scale	[80,81]	Patient interview	Mother/father dyad. Target families	Family functioning style	22 item questionnaire scale (the original scale developed by Deal, Trivette and Dunst, 1988, use a 26-item version) including 3 subscales (interactional patterns and family values, family commitment, intrafamily coping strategies)	5-point Likert scale	Family Functioning Style Model
Instrumental Expressive Social Support Scale (IESS)	[82,83]	Self-reported	Older people. Target community-dwelling older	Social Support	16 items (the original scale used a 20 items version) including 3 subscales (familiar and socio-affective support, sense of control, and financial support)	5-point Likert scale	Literature Review
Important Other Climate Questionnaire (IOCQ)	[58,84]	Self-reported	Patients. Target smokers	Perceived autonomy supportiveness of an "important other"	6 items Unidimensional	7-point Likert scale	Care Climate Questionnaire (HCCQ)
Multidimensional scale of perceived social support (MSPSS)	[26,72,85–88]	Self-reported	Patients. Target women with diabetes and critical social support	Perceived social support	12 items including 3 subscales (family, friends, and significant others)	7-point Likert-type scale	Literature Review
Patient Assessment of Chronic Illness Care-Short Form (PACIC-SF)	[89–92]	Self-reported	Patients. Target primary care patients	Perceived self-management support	11 items Unidimensional scale	5-point Likert-type scale	Chronic Care Model (CCM)
Perceived social support from friends (PSS-Fr) and from family (PSS-Fa) Scales	[22,93]	Self-reported	Students. Target undergraduates	Perceived social support	20 items PSS-Fr Unidimensional scale 20 items PSS-Fa Unidimensional scale	Multichotomous response	Literature Review
Perceptions of Collaboration Questionnaire (PCQ)	[58,94]	Self-reported	Wife and husband dyad. Target married couples	Perceptions of collaboration (solving everyday problems and making decisions)	9 items including 3 subscales (cognitive compensation, interpersonal enjoyment, and frequency of collaboration)	5-point Likert scale	Literature Review
Scales to measure social support for diet and exercise behaviors	[23,93,95–97]	Self-reported	Students and staff. Target psychology students and staff members of a health-promotion research study	Perceived social support specific to health-related eating and exercise behaviors	10-item Social Support for Eating Habits (SSEH) scale: 2 subscales (encouragement; discouragement); 13-item Social Support for Physical Activity (SSPA) scale: 2 subscales (participation, rewards, and punishments)	5-point Likert scale	Literature review and structured in-depth interviews with people who were in the process of changing their diet and/or exercise habits report
Social Provision Scale (SPS)	[21,98,99]	Self-reported	College students and public-school teachers. Target different types of population	Social support	24 items including 6 subscales (attachment, reassurance of worth, reliable alliance, social integration, guidance, and opportunity for nurturance)	4-point Likert scale	Model of the Social Provisions

The type of measure was mostly self-reported. Each instrument reported different constructs of family functioning. As expected, the specific instruments assessed the attributes/actions and family dynamics, and they focused more on diabetes management and the disease challenges. The generic instruments focused more on the families' strengths, weaknesses, values, and behaviors during daily life problems and when facing a problem/adversity.

The Diabetes Family Behavior Checklist (diabetes-specific instrument) and the Family APGAR Index (generic instrument) were the most reported instruments.

3.4. Methodological Quality of Included Studies

The psychometric properties most frequently assessed in each study were structural validity, internal consistency, and construct validity (Supplementary Material File S3).

Of the eighty-one articles included, twenty-seven articles were validation studies, including nineteen original validation studies and eight cultural and linguistic adaptation studies.

The remaining studies did not report sufficient data on the psychometric properties, therefore, it was necessary to include 22 studies as a source of additional information.

Table 2 shows the results of quality assessment of each instrument on the development and content validity using the COSMIN Risk of Bias checklist. The other measurement properties results are displayed in Table 3.

Table 2. Assessment results of each instrument development and content validity according to the COSMIN checklist.

Instrument	References	Instrument Development			Content Validity	Comments
		Design	Cognitive Interview	Total Instrument Development		
Brief Family Assessment Measure (Brief FAM-III)	[65]	A	A	A	A	
	[64]	-	-	-	-	Information about instrument development and content validity not reported
Chronic Illness Resources Survey (CIRS)	[67] [66]	-	-	-	-	Information about instrument development and content validity not reported
Diabetes Caregiver Activity and Support Scale (D-CASS)	[37]	A	-	D	D	Important methodological flaws pilot test and content validity
Diabetes Care Profile (DCP)	[39]	A	-	D	-	Important methodological flaws in the, pilot test and content validity. This instrument evolved from the instrument Diabetes Educational Profile (DEP)
	[38] [7] [40] [41] [42]	-	-	-	-	Information about instrument development and content validity were not reported
Diabetes Family Behavior Checklist (DFBC)	[31]	A	A	A	D	Content validity: important methodological flaws in relevance and comprehensibility (professionals)
	[43] [48] [45] [46] [47] [44]	-	-	-	-	Information about instrument development and content validity were not reported
Diabetes Family Behavior Checklist-II (DFBC-II)	[29] [51] [49] [50] [52]	-	-	-	-	Information about instrument development and content validity were not reported
Diabetes Family Support and Conflict scale (DFSC)	[53]	A	A	A	A	
	[54]	-	-	-	A	Information about instrument development were not reported
Diabetes Mellitus 2 treatment adherence scale version III (EATDM-III)	[55]	-	-	-	D	Information about instrument development were not reported. Not clear if professionals were asked about the relevance of the instrument's items
Diabetes Support Scale (DSS)	[28] [42]	-	-	-	-	Information about instrument development and content validity were not reported
Empowerment questionnaire	[46]	-	-	-	-	This instrument comprised questions from other validated instruments. Information about instrument design, pilot test, and content validity were not reported
Family Adaptability and Cohesion Evaluation Scale (FACES IV)	[69] [70] [68]	-	-	-	-	This instrument was the latest version of the original FACES Information about instrument design, pilot test, and content validity were not reported
Family APGAR Index	[30] [32] [73] [74] [72] [71] [15]	-	-	-	-	Information about instrument development and content validity were not reported
Family Assessment Device (FAD)	[27] [75] [76] [16] [77]	-	-	-	-	Information about instrument development and content validity were not reported

Table 2. *Cont.*

Instrument	References	Instrument Development			Content Validity	Comments
		Design	Cognitive Interview	Total Instrument Development		
Family-Carer Diabetes Management Self-Efficacy Scale (F-DMSES)	[56]	A	A	A	D	Content validity: small number of professionals involved in relevance evaluation
Family Emotional Involvement and Criticism Scale (FEICS)	[24]	A	D	D	D	Important methodological flaws in the design, pilot test, and content validity
	[78]	-	-	.	-	Information about instrument development and content validity were not reported
	[58]					
Family and Friend Involvement in Adults' Diabetes (FIAD)	[93]	A	A	A	A	
	[58]	-	-	-	-	Information about instrument development and content validity were not reported
Family Function Questionnaire (FFQ)	[79]	A	A	A	D	Content validity: not clear about number of, or if, professionals were asked about relevance and comprehensiveness
	[17]	-	-	-	-	Information about instrument development and content validity were not reported
Family Functioning Style Scale	[81]	-	-	-	-	Information about instrument development and content validity were not reported
	[80]					
Family Support Scale adapted for African American women with type 2 Diabetes Mellitus (FSS-AA)	[59]	A	A	A	D	Content validity: the number of professionals involved in data analysis was not clear
Helping for Health Inventory: Couples Version (HHI-C)	[60]	-	-	-	-	Information about instrument development and content validity were not reported
Instrumental Expressive Social Support Scale (IESS)	[83]	-	-	-	-	Information about instrument development and content validity were not reported
	[82]					
Important Other Climate Questionnaire (IOCQ)	[84]	A	D	D	D	Important methodological flaws in the design, pilot test, and content validity.
	[58]	-	-	-	-	Information about instrument development and content validity were not reported
Multidimensional Diabetes Questionnaire (MDQ)	[25]	A	D	D	D	Cognitive interview: it was not clear if the patients were asked about comprehensibility and comprehensiveness; Content validity: it was not clear how many professionals were involved and if they were asked about the relevance and comprehensiveness of the items
	[61]	-	-	-	-	Information about instrument development and content validity were not reported
Multidimensional scale of perceived social support (MSPSS)	[26]	A	D	D	D	Cognitive interview: it was not clear if the patients were asked about comprehensibility and comprehensiveness; Content validity: it was not clear how many professionals were involved in data analysis and if they were asked about the relevance and comprehensiveness of the items
	[86]	A	D	D	D	
	[87]					
	[72]	-	-	-	-	Information about instrument development and content validity were not reported
	[85]					
	[88]					
Patient Assessment of Chronic Illness Care-Short Form (PACIC-SF)	[89]	A	-	D	-	No information about cognitive interview and about content validity
	[90]					
	[91]	-	-	-	-	Information about instrument development and content validity were not reported
	[92]					
Perceived social support from friends (PSS-Fr) and from family (PSS-Fa) Scales	[22]	A	-	D	-	No information about cognitive interview or about content validity
	[93]	-	-	-	-	Information about instrument development and content validity were not reported
Perceptions of Collaboration Questionnaire (PCQ)	[94]	A	-	D	-	No information about cognitive interview or about content validity
	[58]	-	-	-	-	Information about instrument development and content validity were not reported

Table 2. *Cont.*

Instrument	References	Instrument Development			Content Validity	Comments
		Design	Cognitive Interview	Total Instrument Development		
Scales to measure social support for diet and exercise behaviors	[23]	A	D	D	D	Cognitive interview: it was not clear if the patients were asked about comprehensibility and comprehensiveness of the instrument; Content validity: it was not clear how many professionals were involved in data analysis and if they were asked about the relevance and comprehensiveness of the items
	[97]	A	A	A	A	
	[96] [93] [95]	-	-	-	-	Information about instrument development and content validity were not reported
Social Provision Scale (SPS)	[21]	A	D	D	D	Cognitive interview: it was not clear if patients were asked about the comprehensibility and comprehensiveness of the instrument; Content validity: it was not clear how many professionals were involved in data analysis and if they were asked about the relevance and comprehensiveness of the items
	[98] [99]	-	-	-	-	Information about instrument development and content validity were not reported
Social support scale for self-care in middle-aged patients (S4-MAD)	[62]	A	A	A	A	
Unsupportive social interaction scale (USIS)	[63]	A	A	A	D	Content validity: it was not clear if the patients were asked about the relevance and comprehensiveness of the items

NOTE: "A": Adequate; "D": Doubtful; "-": Information was not reported.

Table 3. Results of assessment of measurement properties according to COSMIN for each instrument.

		Methodological Result							
		Quality							
		Box 3	Box 4	Box 5	Box 6	Box 7	Box 8	Box 9	Box 10
Instrument	References	Structural Validity	Internal Consistency	Cross-Cultural Validity/ Measurement Invariance	Reliability	Measurement Error	Criterion Validity	Hypothesis Testing for Construct Validity	Responsiveness
Brief FAM-III	[65]	I	V		-	-	-	-	-
	[64]	-	-	-	-	-	-	-	-
CIRS	[67]	-	V	-	V	-	-	A	
	[66]	-	I	-	-	-	-	-	-
D-CASS	[37]	A	V	-	V	-	-		-
DCP	[39]	V	V	-	-	-	V	A	
	[38]	-	V	-	-	-	-	-	-
	[7] [40] [41]	-	-	-	-	-	-	-	-
	[42]	-	V	-	-	-	-	-	-
DFBC	[31]	-	V	-	V	-	-	A	
	[43]	-	V	-	-	-	-	-	-
	[48]	-	V	-	-	-	-	-	-
	[45]	A	V	-	I	-		A	
	[46]	-	-	-	-	-	-	-	-
	[47]	-	V	-	-	-	-	-	-
	[44]	-	V	-	-	-	-	-	-

Table 3. *Cont.*

		Methodological Result							
		Quality							
		Box 3	Box 4	Box 5	Box 6	Box 7	Box 8	Box 9	Box 10
Instrument	References	Structural Validity	Internal Consistency	Cross-Cultural Validity/ Measurement Invariance	Reliability	Measurement Error	Criterion Validity	Hypothesis Testing for Construct Validity	Responsiveness
DFBC-II	[29]	-	V	-	V	-	-	A	-
	[51]	-	-	-	-	-	-	-	-
	[49]	-	V	-	-	-	-	-	-
	[50]	-	V	-	-	-	-	-	-
	[52]	-	-	-	-	-	-	-	-
DFSC	[53]	A	V	-	-	-	-	-	-
	[54]	A	V	-	D	-	-	-	-
EATDM-III	[55]	A	V	-	-	-	-	-	-
DSS	[28]	-	V	-	-	-	V	A	
	[42]	-	-	-	-	-	-	-	-
Empowerment questionnaire	[46]	A	V	-	I	-	-	D	-
FACES IV	[69]	V	V	-	-	-	V	-	-
	[70]	-	-	-	-	-	-	-	-
	[68]	-	V	-	-	-	-	-	-
Family APGAR Index	[30]	-	V	-	-	-	-	A	-
	[32]	-	V	-	V	-	-	A	-
	[73]	-	-	-	-	-	-	-	-
	[74]	-	-	-	-	-	-	-	-
	[72]	-	-	-	-	-	-	-	-
	[71]	-	-	-	-	-	-	-	-
	[15]	-	-	-	-	-	-	-	-
FAD	[27]	-	V	-	-	-	V	A	-
	[75]	-	V	-	-	-	-	-	-
	[76]	-	V	-	D	-	-	-	-
	[16]	-	V	-	-	-	-	-	-
	[77]	-	-	-	-	-	-	-	-
F-DMSES	[56]	A	V	-	V	-	-	-	D
FEICS	[24]	-	V	-	-	-	-	-	-
	[78]	V	V	-	-	-	V	A	-
	[58]	-	-	-	-	-	-	-	-
FIAD	[93]	V	V	-	V	-	V	A	-
	[58]	-	V	-	-	-	-	-	-
FFQ	[79]	-	V	-	I	-	-	-	-
	[17]	-	V	-	-	-	-	-	-
Family Functioning Style Scale	[81]	A	V	-	-	-	-	-	-
	[80]	-	-	-	-	-	-	-	-
FSS-AA	[59]	A	V	-	V	-	V	-	-
HHI-C	[60]	-	V	-	V	-	V	-	-
IESS	[83]	-	V	-	-	-	-	-	-
	[82]	V	V	-	-	-	-	A	-
IOCQ	[84]	V	V	-	V	-	-	A	-
	[58]	-	V	-	-	-	-	-	-
MDQ	[25]	V	V	-	D	-	-	A	-
	[61]	-	V	-	-	-	-	-	-

Table 3. *Cont.*

		Methodological Result							
		Quality							
		Box 3	Box 4	Box 5	Box 6	Box 7	Box 8	Box 9	Box 10
Instrument	References	Structural Validity	Internal Consistency	Cross-Cultural Validity/ Measurement Invariance	Reliability	Measurement Error	Criterion Validity	Hypothesis Testing for Construct Validity	Responsiveness
MSPSS	[26]	V	V	-	V	-	-	-	-
	[86]	A	V	-	-	-	V	A	-
	[87]	-	V	-	-	-	-	-	-
	[72]	-	-	-	-	-	-	-	-
	[85]	-	V	-	-	-	-	-	-
	[88]	-	-	-	-	-	-	-	-
PACIC-SF	[89]	A	V	-	-	-	-	A	-
	[90]	-	-	-	-	-	-	-	-
	[91]	-	-	-	-	-	-	-	-
	[92]	-	-	-	-	-	-	-	-
PSS-Fr and PSS-Fa	[22]	A	V	-	-	-	-	-	-
	[93]	-	V	-	-	-	-	-	-
PCQ	[94]	V	V	-	-	-	-	-	-
	[58]	-	V	-	-	-	-	-	-
Scales to measure social support for diet and exercise behaviors	[23]	A	V	-	D	-	V	A	-
	[97]	V	V	-	-	-	-	-	-
	[96]	-	V	-	-	-	-	-	-
	[93]	-	V	-	-	-	-	-	-
	[95]	-	V	-	-	-	-	-	-
SPS	[21]	V	V	-	-	-	-	A	-
	[98]	-	V	-	-	-	-	-	-
	[99]	-	V	-	-	-	-	-	-
S4-MAD	[62]	V	V	-	V	-	-	-	-
USIS	[63]	A	V	-	A	-	-	A	-

Note: Brief FAM-III: Brief Family Assessment Measure-Brief; CIRS: Chronic Illness Resources Survey; D-CASS: Diabetes Caregiver Activity and Support Scale; DCP: Diabetes Care Profile; DFBC: Diabetes Family Behavior Checklist; DFBC-II: Diabetes Family Behavior Checklist-II; DFSC: Diabetes Family Support and Conflict scale; EATDM-III: Diabetes Mellitus 2 treatment adherence scale version III; DSS: Diabetes Support Scale; FACES IV: Family Adaptability and Cohesion Evaluation Scale; FAD: Family Assessment Device; F-DMSES: Family-Carer Diabetes Management Self- Efficacy Scale; FEICS: Family Emotional Involvement and Criticism Scale; FIAD: Family and Friend Involvement in Adults' Diabetes; FFQ: Family Function Questionnaire; FSS-AA: Family Support Scale adapted for African American women with type 2 Diabetes Mellitus; HHI-C: Helping for Health Inventory: Couples Version; IESS: Instrumental Expressive Social Support Scale; IOCQ: Important Other Climate Questionnaire; MDQ: Multidimensional Diabetes Questionnaire; MSPSS: Multidimensional scale of perceived social support; PACIC-SF: Patient Assessment of Chronic Illness Care-Short Form; PSS-Fr: Perceived social support from friends; PSS-Fa: Perceived social support from family; PCQ: Perceptions of Collaboration Questionnaire; SPS: Social Provision Scale; S4-MAD: Social support scale for self-care in middle-aged patients; USIS: Unsupportive social interaction scale. "V": Very Good; "A": Adequate; "D": Doubtful; "I": Inadequate; "-": Information was not reported.

Ten studies presented information about the instrument development, which was scored as adequate, and twelve studies had a doubtful score. The remaining studies did not report information about the instrument development.

According to the COSMIN Risk of Bias checklist, six studies were assigned an adequate score based on the content validity, and fourteen studies had a doubtful score. The remaining studies did not report information on content validity.

The structural validity was assessed in twenty-seven studies through a confirmatory or exploratory factor analysis: twelve studies were rated as very good in terms of structural validity, fourteen were rates as adequate, and one was rates as inadequate.

The internal consistency was assessed in 63 studies and, for the most part [56], the authors reported this measurement property using Cronbach's alpha values. One study used the reliability coefficient. Internal consistency was generally scored as very good, except in one study that was scored as insufficient, in which the authors only reported Cronbach's alpha value of the total scale.

Reliability was assessed using the test–retest methodology in seventeen studies and through correlation coefficients in three studies. The other studies did not include the assessment of reliability. By considering the time of two weeks as an appropriate time interval, according to similar studies [100], twelve studies were rated as very good, and four studies were rated as doubtful. One study did not state the time interval. Three studies were rated as inadequate because the interval was not appropriate.

Family functioning is a multidimensional construct, therefore, the literature does not recognize a gold standard instrument that can be used to assess this construct. However, ten studies assessed the concurrent validity comparing the instrument to other well-established instruments that assess similar constructs. In these studies, the criterion validity was rated as very good.

Hypotheses testing for construct validity was assessed by comparing it with other similar outcome measurement instruments in 12 studies and by comparing between the subgroups in eight studies. Only one study was rated as doubtful due to it having a poor description of the characteristics of the subgroups. The remaining studies were scored as adequate, as not all of the important characteristics of the subgroups had been described, and there were doubts about whether the comparator instrument was appropriate for the study population or not.

Responsiveness was reported in one study using a construct approach (before and after the intervention), and because there was a poor description of the intervention, it was rated as doubtful.

No other psychometric characteristics were described.

3.5. Quality of Psychometric Properties of Instruments

The measurement properties for each instrument were described and evaluated according to the updated criteria for good measurement properties [34], and they are presented in alphabetic order in Table 4.

Table 4. Rating scores of measurement properties for each instrument.

Instrument	References	Rating Scores of Measurement Properties							
		Structural Validity	Internal Consistency	Cross-Cultural Validity/ Measurement Invariance	Reliability	Measurement Error	Criterion Validity	Hypothesis Testing for Construct Validity	Responsiveness
Brief FAM-III	[65]	–	+	NR	NR	NR	NR	NR	NR
	[64]	NR	NR	NR	NR	NR	NR	NR	NR
CIRS	[67]	NR	–	NR	+	NR	NR	?	NR
	[66]	NR	–	NR	NR	NR	NR	NR	NR
D-CASS	[37]	–	+	NR	+	NR	NR	NR	NR
DCP	[39]	?	–	NR	NR	NR	–	+	NR
	[38]	NR	+	NR	NR	NR	NR	NR	NR
	[7]	NR	NR	NR	NR	NR	NR	NR	NR
	[40]	NR	NR	NR	NR	NR	NR	NR	NR
	[41]	NR	+	NR	NR	NR	NR	NR	NR
	[42]	NR	NR	NR	NR	NR	NR	NR	NR

Table 4. *Cont.*

Instrument	References	Rating Scores of Measurement Properties							
		Structural Validity	Internal Consistency	Cross-Cultural Validity/ Measurement Invariance	Reliability	Measurement Error	Criterion Validity	Hypothesis Testing for Construct Validity	Responsiveness
DFBC	[31]	NR	–	NR	–	NR	NR	–	NR
	[43]	NR	–	NR	NR	NR	NR	NR	NR
	[48]	NR	+	NR	NR	NR	NR	NR	NR
	[45]	?	+	NR	+	NR	NR	NR	NR
	[46]	NR	NR	NR	NR	NR	NR	NR	NR
	[47]	NR	+	NR	NR	NR	NR	NR	NR
	[44]	NR	+	NR	NR	NR	NR	NR	NR
DFBC-II	[29]	NR	–	NR	?	NR	NR	NR	NR
	[51]	NR	NR	NR	NR	NR	NR	NR	NR
	[49]	NR	+	NR	NR	NR	NR	NR	NR
	[50]	NR	+	NR	NR	NR	NR	NR	NR
	[52]	NR	NR	NR	NR	NR	NR	NR	NR
DFSC	[53]	–	+	NR	NR	NR	NR	NR	NR
	[54]	+	+	NR	?	NR	NR	NR	NR
EATDM-III	[55]	-	+	NR	NR	NR	NR	NR	NR
DSS	[28]	NR	+	NR	NR	NR	–	–	NR
	[42]	NR	NR	NR	NR	NR	NR	NR	NR
Empowerment questionnaire	[46]	?	+	NR	–	NR	NR	?	NR
FACES IV	[69]	+	+	NR	NR	NR	+	+	NR
	[70]	NR	NR	NR	NR	NR	NR	NR	NR
	[68]	NR	+	NR	NR	NR	NR	NR	NR
Family APGAR Index	[30]	NR	–	NR	NR	NR	NR	+	NR
	[32]	NR	+	NR	+	NR	NR	NR	NR
	[73]	NR	NR	NR	NR	NR	NR	NR	NR
	[74]	NR	NR	NR	NR	NR	NR	NR	NR
	[72]	NR	NR	NR	NR	NR	NR	NR	NR
	[71]	NR	NR	NR	NR	NR	NR	NR	NR
	[15]	NR	NR	NR	NR	NR	NR	NR	NR
FAD	[27]	NR	+	NR	NR	NR	–	NR	NR
	[75]	NR	+	NR	NR	NR	NR	NR	NR
	[76]	NR	–	NR	?	NR	NR	NR	NR
	[16]	NR	+	NR	NR	NR	NR	NR	NR
	[77]	NR	NR	NR	NR	NR	NR	NR	NR
F-DMSES	[56]	–	+	NR	–	NR	NR	NR	–
FEICS	[24]	NR	+	NR	NR	NR	NR	NR	NR
	[78]	–	+	NR	NR	NR	–	+	NR
	[58]	NR	NR	NR	NR	NR	NR	NR	NR
FIAD	[93]	+	–	NR	–	NR	–	+	NR
	[58]	NR	+	NR	NR	NR	NR	NR	NR
FFQ	[79]	NR	–	NR	–	NR	NR	+	NR
	[17]	NR	+	NR	NR	NR	NR	NR	NR
Family Functioning Style Scale	[81]	-	+	NR	NR	NR	NR	NR	NR
	[80]	NR	NR	NR	NR	NR	NR	NR	NR
FSS-AA	[59]	–	+	NR	–	NR	–	–	NR
HHI-C	[60]	NR	–	NR	?	NR	–	–	NR
IESS	[83]	NR	+	NR	NR	NR	NR	NR	NR
	[82]	–	+	NR	NR	NR	NR	NR	NR

Table 4. *Cont.*

Instrument	References	Rating Scores of Measurement Properties							
		Structural Validity	Internal Consistency	Cross-Cultural Validity/ Measurement Invariance	Reliability	Measurement Error	Criterion Validity	Hypothesis Testing for Construct Validity	Responsiveness
IOCQ	[84]	+	+	NR	–	NR	NR	–	NR
	[58]	NR	+	NR	NR	NR	NR	NR	NR
MDQ	[25]	+	+	NR	?	NR	NR	NR	NR
	[61]	NR	+	NR	NR	NR	NR	NR	NR
MSPSS	[26]	–	+	NR	?	NR	NR	NR	NR
	[86]	–	+	NR	NR	NR	–	+	NR
	[87]	NR	+	NR	NR	NR	NR	NR	NR
	[72]	NR	NR	NR	NR	NR	NR	NR	NR
	[85]	NR	+	NR	NR	NR	NR	NR	NR
	[88]	NR	NR	NR	NR	NR	NR	NR	NR
PACIC-SF	[89]	–	+	NR	NR	NR	NR	+	NR
	[90]	NR	NR	NR	NR	NR	NR	NR	NR
	[91]	NR	NR	NR	NR	NR	NR	NR	NR
	[92]	NR	NR	NR	NR	NR	NR	NR	NR
PSS-Fr and PSS-Fa	[22]	?	+	NR	NR	NR	NR	NR	NR
	[93]	NR	+	NR	NR	NR	NR	NR	NR
PCQ	[94]	–	–	NR	NR	NR	NR	NR	NR
	[58]	NR	–	NR	NR	NR	NR	NR	NR
Scales to measure social support for diet and exercise behaviors	[23]	–	–	NR	?	NR	–	–	NR
	[97]	+	+	NR	NR	NR	NR	NR	NR
	[96]	NR	+	NR	NR	NR	NR	NR	NR
	[93]	NR	+	NR	NR	NR	NR	NR	NR
	[95]	NR	–	NR	NR	NR	NR	NR	NR
SPS	[21]	–	–	NR	NR	NR	NR	+	NR
	[98]	NR	–	NR	NR	NR	NR	NR	NR
	[99]	NR	–	NR	NR	NR	NR	NR	NR
S4-MAD	[62]	+	+	NR	+	NR	NR	NR	NR
USIS	[63]	–	+	NR	?	NR	NR	NR	NR

Note: "+" = sufficient; "–"= insufficient, "?" = indeterminate; NR = measurement was not reported. Brief FAM-III: Brief Family Assessment Measure-Brief; CIRS: Chronic Illness Resources Survey; D-CASS: Diabetes Caregiver Activity and Support Scale; DCP: Diabetes Care Profile; DFBC: Diabetes Family Behavior Checklist; DFBC-II: Diabetes Family Behavior Checklist-II; DFSC: Diabetes Family Support and Conflict scale; EATDM-III: Diabetes Mellitus 2 treatment adherence scale version III; DSS: Diabetes Support Scale; FACES IV: Family Adaptability and Cohesion Evaluation Scale; FAD: Family Assessment Device; F-DMSES: Family-Carer Diabetes Management Self-Efficacy Scale; FEICS: Family Emotional Involvement and Criticism Scale; FIAD: Family and Friend Involvement in Adults' Diabetes; FFQ: Family Function Questionnaire; FSS-AA: Family Support Scale adapted for African American women with type 2 Diabetes Mellitus; HHI-C: Helping for Health Inventory: Couples Version; IESS: Instrumental Expressive Social Support Scale; IOCQ: Important Other Climate Questionnaire; MDQ: Multidimensional Diabetes Questionnaire; MSPSS: Multidimensional scale of perceived social support; PACIC-SF: Patient Assessment of Chronic Illness Care-Short Form; PSS-Fr: Perceived social support from friends; PSS-Fa: Perceived social support from family; PCQ: Perceptions of Collaboration Questionnaire; SPS: Social Provision Scale; S4-MAD: Social support scale for self-care in middle-aged patients; USIS: Unsupportive social interaction scale.

Brief Family Assessment Measure (Brief FAM-III): This instrument was used in two studies [64,65]. One study [65] reported the structural validity, which was rated as insufficient due to the absence of criteria for a sufficient status, and the internal consistency rated as sufficient.

Chronic Illness Resources Survey (CIRS): Internal consistency was rated as insufficient in both of the studies that reported this instrument [66,67]. These results were explained by Cronbach's alpha value ≤ 0.70 [67] and the missing reported values of this measurement property in the instrument' subscales [66]. One of the studies [67] reported the reliability

rated as sufficient for correlations with other instruments for related constructs > 0.30. The construct validity was rated as indeterminate due to it having insufficient information.

Diabetes Caregiver Activity and Support Scale (D-CASS): This instrument was reported in one study [37]. Structural validity was assessed through exploratory factor analysis, and it missing other information meant that was rated as insufficient. Internal consistency and reliability were rated as sufficient.

Diabetes Care Profile (DCP): Six studies reported this instrument [7,38–42]. Structural validity was described in one study [39], and it was rated as indeterminate for having insufficient information. Also, the criterion validity was scored as insufficient for the correlations values. The construct validity was scored as sufficient. Three studies reported internal consistency, two studies were rated as sufficient [38,41], and one study was as insufficient [39] for Cronbach's alpha value ≤ 0.70 in the subscales.

Diabetes Family Behavior Checklist (DFBC): This instrument was tested in seven studies [31,43–48]. One study's reported structural validity was rated as indeterminate due to it lacking information [45]. The internal consistency was reported in six studies. Four studies were scored as sufficient [44,45,47,48], and two studies were scored as insufficient [31,43] as they had Cronbach's alpha values ≤ 0.70. The hypothesis testing for construct validity was reported in one study [31], and it was rated as insufficient, which was justified by the correlations values ($r < 0.30$).

Diabetes Family Behavior Checklist-II (DFBC-II): Five studies tested this instrument [29,49–52]. One study [29] assessed the internal consistency and reliability. The internal consistency was rated as insufficient (Cronbach's value in one subscale < 0.70). Reliability was scored as indeterminate when the studies were missing Intraclass Correlation Coefficient (ICC) values. The internal consistency, which was reported in two studies [49,50], was rated as sufficient.

Diabetes Family Support and Conflict Scale (DFCS): Two studies reported the structural factor validity [53,54]. One study was rated as sufficient [54], and the other one was rated as insufficient [53] for lacking all of the relevant information. The internal validity was reported as sufficient in both of the studies. The reliability was scored as indeterminate in Sofulu et al. study because it contained insufficient information [54].

Diabetes Mellitus 2 Treatment Adherence Scale version III (EATDM-III): this scale was reported in one study [55]. The exploratory factor analysis was performed and scored as insufficient due to it having missing information. The internal consistency was scored as sufficient.

Diabetes Support Scale (DSS): This scale was tested in two studies [28–42]. One study [28] described the internal consistency score as sufficient. For the low criterion validity, the correlation value ($r < 0.70$) was rated as insufficient. Similarly, the construct validity was scored as insufficient ($r < 0.30$).

Empowerment Questionnaire: This scale was evaluated in one study [46]. The internal consistency was rated as sufficient. The structural validity and construct validity were scored as indeterminate due to it having insufficient information. The reliability was scored as insufficient (r values ≥ 0.56).

Family Adaptability and Cohesion Evaluation Scale (FACES IV): This instrument was tested in three studies [68–70]. Only one of these studies reported the structural validity, internal consistency, criterion validity, and construct validity; all of them were scored as sufficient [69]. Another study reported the internal consistency, and we scored it as sufficient [68].

Family APGAR Index: The measurement properties of this instrument were reported in two out of the seven studies [15,30,32,71–74] that used this instrument. One study [30] assessed the internal consistency, and we rated it as insufficient (Cronbach value < 0.70), and the construct validity score was sufficient. Another study [32] reported internal consistency and reliability, and we scored both as sufficient.

Family Assessment Device (FAD): This scale was reported in five studies [16,27,75–77]. The internal consistency was rated as sufficient in three studies [16,27,75], whereas it was as

insufficient in the study of He et al. [76] due to it having alpha de Cronbach' values of 0.53. The reliability was scored as indeterminate because it did not describe the ICC values [76]. In the study by Epstein et al. [27], for correlations values < 0.70, the criterion validity was considered to be insufficient.

Family-Carer Diabetes Management Self-Efficacy Scale (F-DMSES): One study evaluated this scale [56] and described the measurement properties. The internal consistency was scored as sufficient. The structural validity (lack of criteria for sufficient), the reliability (ICC value < 0.70), and the criterion validity (r < 0.70) were scored as insufficient.

Family Emotional Involvement and Criticism Scale (FEICS): This scale was tested in three studies [24,58,78]. Two studies reported the internal consistency, and we scored it as sufficient [24,78]. One study [24] assessed the structural validity, which we rated as insufficient. The same study was scored as sufficient in terms of construct validity and as insufficient in terms of criterion validity (r < 0.70).

Family and Friend Involvement in Adults' Diabetes (FIAD): Two studies used this instrument [57,58]. One study reported the internal consistency' value, which we scored as sufficient [58]. The other study [57] reported the structural and construct validity, and both of the properties were rated as sufficient. This study also assessed the internal consistency, criterion validity, and reliability, which were all rated as insufficient (values of each measurement property reported < 0.70).

Family Function Questionnaire (FFQ): This instrument was tested in two studies [17,79]. One study [79] reported the internal consistency and reliability, which we rated as insufficient due to it having low values (Cronbach's alpha and ICC < 0.70). However, the construct validity was scored as sufficient. The study by Pamungkas and Chamroonsawasdi [17] assessed the internal consistency, which we rated as sufficient.

Family Functioning Style Scale: Two studies described this instrument [80,81]. Only one study [81] assessed the measurement properties. The internal consistency was rated as sufficient, and the structural validity was rated as indeterminate, which were justified by the paper lacking information.

Family Support Scale adapted for African American women with type 2 Diabetes Mellitus (FSS-AA): The study by Littlewood et al. [59] reported internal consistency, which was scored as sufficient. The other measurement properties, the structural validity (criteria for sufficient not reported), reliability (ICC value < 0.70), criterion validity (correlations < 0.70), and construct validity (r < 0.30), were rated as insufficient.

Helping for Health Inventory Couples version (HHI-C): One study [60] described this instrument. The internal consistency and criterion validity were described, and we scored them as insufficient (Cronbach value in one of the subscales and correlations values were both <0.70). The reliability was scored as indeterminate (missing values). The construct validity was rated as insufficient (r < 0.30).

Instrumental Expressive Social Support Scale (IESS): This scale was reported in two studies [82,83]. One study [83] described the internal consistency, and we scored it as sufficient. The other study [82] reported the structural validity (rated as insufficient as criteria for sufficient not met), and the internal consistency was scored as sufficient.

Important Other Climate Questionnaire (IOCQ): Two studies tested this instrument [58,84]. The internal consistency was reported, and we scored as sufficient in both of the studies. Only one study [84] described the structural validity (rated as sufficient), and the construct validity was rated as insufficient due to it having low correlations values (r < 0.30), and the reliability was rated as insufficient due to it having missing information.

Multidimensional Diabetes Questionnaire (MDQ): The internal consistency was reported, and we scored it as sufficient in the two studies that tested this instrument [25,61]. The structural validity was rated as sufficient in study by Talbot et al. [25] and, in contrast, the reliability was rated as indeterminate due to it missing information.

Multidimensional Scale of Perceived Social Support (MSPSS): Four out of six studies [26,72,85–88] that used this instrument, and we scored the internal consistency as sufficient [26,85–87]. Two studies [26,86] assessed the structural validity scored as insuffi-

cient (criteria for sufficient not met). The reliability was evaluated by Zimet et al. [26], and we scored it as indeterminate (values not reported). One study also assessed the criterion validity and the construct validity [86]: the first one was rated as insufficient (values of correlations < 0.70, and the second one was scored as sufficient.

Patient Assessment of Chronic Illness Care-Short Form (PACIC-SF): Only one study of the four studies [89–92] described the psychometric properties. This study [89] reported the internal consistency and construct validity, and both of them were rated as sufficient, and the structural validity was scored as insufficient (criteria for sufficient not described).

Perceived Social Support from Friends (PSS-Fr) and from Family (PSS-Fa) scales: The internal consistency was reported, and we rated it as sufficient in two studies [22,93]. However, the structural validity was reported in only one study [22], and we rated as indeterminate due to it lacking information.

Perceptions of Collaboration Questionnaire (PCQ): This instrument was tested in two studies [58,94]. One study [94] was assessed and the structural validity (criteria for sufficient not described) and the internal consistency (Cronbach's alpha value < 0.70) were scored as insufficient. The study by Mayberry et al. [58] described the internal consistency, which as rated as insufficient (Cronbach's alpha value in one subscale < 0.70).

Scales to measure social support for diet and exercise behaviors: The internal consistency was described in the five studies that tested this scale [23,93,95–97]. Three studies were rated as sufficient [93,96,97] and the remaining two studies were rated as insufficient as the reported Cronbach's values were < 0.70 [23,95]. The construct validity was reported in one study [23] and it was scored as insufficient (correlations' values < 0.30). These authors also reported the structural validity (rated as insufficient for having insufficient criteria), criterion validity (rated as insufficient for having a correlation´s value < 0.70), and reliability (rated as indeterminate for missing values of ICC).

Social Provisions Scale (SPS): The internal consistency was reported, and we rated it as insufficient in the three studies that tested this instrument for having subscale Cronbach's values < 0.70 [21] and for having missing information [98,99]. Cutrona and Russell [21] also described the structural validity, and we rated it as insufficient due to the absence of information, and we rated the construct validity as sufficient.

Social Support Scale for Self-care in Middle-Aged Patients (S4-MAD): Naderimagham et al. [62] developed this instrument and reported structural validity, internal consistency, and reliability. All of the measurement properties were rated as sufficient.

Unsupportive Social Interaction Scale (USIS): The study by Baron-Epel et al. [63] reported the internal consistency, which we scored as sufficient. Contrarily, the structural validity was rated as insufficient due to it lacking information, and the reliability was indeterminate due to it lacking an ICC value.

4. Discussion

This study was conducted to systematically assess the psychometric quality of the instruments developed and used to assess the family functioning of the families of people with diabetes.

We identified 31 instruments focused on different constructs of family functioning which were used in different settings. The majority of the instruments were used in multiple studies, with the exception of eight instruments that were tested in only one study.

This review identified 49 studies that reported insufficient data on the instrument measurement properties. This lack of information led to the need to screen 22 additional sources of psychometric information using the references provided by the authors of the studies. Nevertheless, the studies developed by Takenaka et al. [70] and Regufe [83] were exceptions. In these two studies, the full-text instrument validation was not available to be consulted. For that reason, the original version of FACES IV [69] and the validation study of the IESS, which was also developed in Portugal [82] were retrieved.

None of the psychometric properties of the included instruments in this review were scored as "very good". This can be explained by the them missing reported values or lacking criteria described in the COSMIN Risk of Bias checklist [34].

Terwee et al. [36] considered content validity to be the most important measurement property when one is selecting an instrument. However, we observed that the content validity was inadequately reported or not reported, except in the validation studies. Only five instruments were rated as adequate in terms of the content validity (Brief FAM-III, DFSC, FIAD, Scales to measure social support for diet and exercise behaviors, and S4-MAD). We found instruments that were developed from other(s) instrument(s), and for that reason, some information was not clearly or sufficiently reported (DFBC, DCP, and Empowerment questionnaire).

Furthermore, the sources of additional psychometric information identified also missed information about content validity and instrument development according to COSMIN criteria.

Most of the instruments were scored as doubtful for content validity due to them lacking information or because it was not clear if the professionals were asked about the relevance and comprehensiveness of the items and/or if the patients were asked about comprehensiveness and comprehensibility.

In addition, some essential psychometric properties were not tested for many of the instruments, or they were rated as insufficient. For most of the studies, the structural validity was not reported, and when it was reported, only seven studies met all of the criteria for a "sufficient" score.

Some studies were rated as insufficient in terms of the internal consistency. This score can be explained because the authors only reported Cronbach's alpha values for the total scale, missing the subscales or the values [66] or for the correlation´s value < 0.70, e.g., the studies by Fitzgerald et al. [39]; Glasgow et al. [67]; Mayberry et al. [58]. Cross-cultural validity and measurement errors were not reported anywhere.

Of the twenty studies that reported reliability, only five of them were scored as "sufficient".

Family functioning is a multidimensional construct, and it is associated with the people with diabetes' perception of their family's involvement and support [17], which may explain the diversity of the constructs assessed in each identified instrument. Regarding the specific instruments used to assess the families of people with diabetes, the majority of them focused on specific aspects of diabetes management and the social and psychological factors related to diabetes. These instruments seem to be helpful for researchers who want to investigate the effectiveness of a specific intervention in diabetes-related family behaviors through a longitudinal design. Concerning the generic instruments, the constructs were focused on family adaptability, strengths and weaknesses, different types of social support, perceived social support, and family communication, and coping strategies.

By recognizing the family support as being crucial in diabetes care, some instruments (e.g., DSS; FSS-AA) have been developed and used to assess only the supportive behaviors in the families of people with diabetes. However, people with diabetes described sabotaging their family's behaviors, most commonly regarding diet and exercise [51]. In comparison, other instruments were developed to assess not only the support, but also the non-supportive behaviors (DFBC), the family conflict (DFCS), the helpful and harmful involvement (FIAD), partner investment and resistance (HHI-C), or only the unsupportive social interactions (USIS).

Thus, nurses should recognize that the family environment and their involvement may not always have a health-promoting impact on diabetes and the respective outcomes [53]. The helpful and harmful aspects of family/friend involvement and supportive and non-supportive behaviors should be considered when the family is assessed [57].

Although most of the instruments included in this review, disease-specific or generic ones, were multidimensional and developed to assess multiple family attributes, some instruments are focused only on assessing one specific family attribute, such as the marital

dyad, criticism, emotional involvement, or treatment adherence. These instruments are described as unidimensional (e.g., D-CASS and PACIC-SF).

The DFBC was the disease-specific instrument that was most frequently reported, and it targets not only the patient, but also the family members. This instrument was composed by two subscales (supportive and non-supportive family behaviors). The Family APGAR Index was the generic instrument that was most frequently tested.

Regarding the overview of the quality appraisal of all of the instruments in terms of development and content validity and considering the instruments that were scored as adequate in terms of both of them according to the COSMIN methodology, these allow us to highlight the Brief FAM-III, the DFSC, FIAD, the Scales to measure social support for diet and exercise behaviors and S4-MAD instruments.

The Scales to measure social support for diet and exercise behaviors, for its specificity, although it is very important in families with people with diabetes, could be insufficient in recognizing and understanding the family functions that promote the family involvement in the behavioral challenges that the disease requires.

The S4-MAD scale was developed to assess the self-care social support in diabetic patients that are middle ages, considering that most of the patients are this age. This instrument emphasizes the importance of all forms of social support in diabetes management and metabolic control. However, it is important to mention that social support in general, which is recognized in the literature as a determining factor for the success of the different approaches developed with people with diabetes and their families, can also be a source of conflict and stress [53].

Thus, the other scales can be used to assess important family' behaviors: diabetes-specific instruments allow us to assess the helpful and harmful aspects of family and friend involvement in the lives of adults with diabetes (FIAD) and the supportive and non-supportive behaviors of families with people with diabetes (DFSC).

Other instruments emphasize the other dimensions of social support, and for that reason, they can be considered to be valid options for assessing family functioning from a more holistic perspective. The Brief FAM-III scale allows us to perform an assessment of the family functioning from different perspectives (the family as a system, the relationships between specific pairs in the family, and the individual's perception of their functioning in the family). Although it is a generic instrument, it allows us to identify the family's perceptions of the strengths and weaknesses in their family functioning.

Diabetes is described as "a pandemic of unprecedented magnitude which is spiraling out of control" [1]. The International Diabetes Federation reports a global increase in diabetes prevalence, and this presents a challenge to the health and well-being of people with diabetes, family, and society [1]. This information has exposed the fragility of the actual approaches and the importance of identifying new strategies that are meant to be more effective in controlling and managing diabetes.

The interventions should be developed for people with diabetes and their family and according to the specificities of their social and living situations.

Therefore, in families with people with diabetes, it is crucial that nurses identify, through valid instruments, the relationships established between the family members and their behaviors. As it has already been mentioned, not all of the support and involvement from family is perceived as positive by people with diabetes. Nurses should recognize behaviors that are an incentive, obstacles, or barriers to disease management [4] assessing family and promoting their involvement in diabetes challenges.

However, it is recommended that health professionals do not develop more instruments, but instead, they should invest in deepening their knowledge of the existing instruments, their characteristics, and their psychometric properties.

Therefore, the decision to use one instrument should be made based on a quality appraisal of the measurement properties of the instrument and by taking into consideration the country, the target population, and the goals of the study.

Strengths and Limitations

We have developed an extensive systematic review of family functioning instruments in families with people with diabetes, including grey literature. Regardless of our decision to limit the search strategy to 2010, by continuing another study in this area [19], we performed reference screening, irrespective of the year of publication, as a source of additional information. This fact is considered to be a strength of this study by the authors.

We considered the COSMIN guidelines and updated the quality criteria for good psychometric properties to assess the quality of each study and each measurement property [34–36], which is an important strength of this study.

Most of the studies included in this systematic review were conducted before the establishment of COSMIN guidelines, thus, some measurement properties and instrument development criteria were not reported in these studies. This can justify some of the results presented in the rating scores summary. Another important fact to note is the differences between the countries in their guidelines to assess the measurement properties, and in this review, we included studies from different countries.

By considering family functioning as a multidimensional construct, we may have made errors in the study identification, given the number of results obtained.

Another potential limitation of this study is the variety of studies and instruments that we included. We described 31 instruments to assess the family functioning of families of people with diabetes, which were developed and tested in different countries, settings, and among different target populations.

5. Conclusions

This systematic review provides an overview of the instruments that are currently used to assess the functioning of the family of people with diabetes, and it reports their measurement properties and ratings. It can be an important resource to help nurses to select the adequate instrument for their clinical practice and research in different settings and according to the construct that is being assessed.

Although 31 instruments were included, none of their psychometric properties were scored as "very good" according to the COSMIN Risk of Bias checklist. Considering the instruments that were scored as adequate in terms of development and content validity, five instruments were highlighted according to the updated criteria for having good measurement properties.

The development of new instruments is not recommended. Instead, more studies should be conducted on the existing instruments to assess the less frequently evaluated psychometric properties, namely, reliability, measurement error, and responsiveness.

The target population of the studies should consider a diversity of family members, thus adapting to the evolution of the concept of family by not only restricted it people with blood ties.

Using valid instruments to develop and evaluate interventions in families with diabetes is essential to promote health literacy, namely, critical literacy and the effectiveness of diabetes management.

Supplementary Materials: The following supporting information can be downloaded at: https://www.mdpi.com/article/10.3390/ijerph20021325/s1, Table S1: Search strategy used for Medline; Table S2: Summary information of each included study in chronological order; Table S3: Summary of results for measurement properties for each instrument.

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ARTIGO: *Effectiveness of family-focused interventions for adults with diabetes: an Umbrella Review* – **Artigo submetido para publicação no *Journal of Clinical Nursing***

TITLE: Effectiveness of family-focused interventions for adults with diabetes: an Umbrella Review

ABSTRACT

Aim: To synthesize existing evidence on family-focused interventions for adults with diabetes and assess their effectiveness on patient and family outcomes.
Design: Umbrella review.
Methods: This umbrella review followed the Joanna Briggs Institute methodology. Systematic reviews published between 2013 and 2024 were analyzed, and methodological quality was assessed using the Critical Appraisal Checklist for Systematic Reviews and Research Syntheses.
Data Sources: MEDLINE®, CINAHL®, Scopus®, Cochrane Library, SciELO, PsycINFO, and JBI Evidence Synthesis were searched for relevant reviews. The gray literature was identified from the Scientific Open Access Repository of Portugal and OpenGrey.
Results: Five systematic reviews of varying methodological quality were included. Family-focused interventions demonstrated positive effects on glycemic control, adherence to self-management behaviors, and psychological well-being. Additionally, family members benefited through increased diabetes knowledge and engagement in care. However, most reviews lacked details on family involvement strategies and did not fully explore the impact of participant diversity.
Conclusions: The review highlights the effectiveness of family-focused interventions in diabetes management but underscores the need for tailored approaches that meaningfully engage families while addressing broader health determinants, including social, cultural, and economic factors.
Implications for the Profession and/or Patient Care: Family involvement is essential in diabetes care, directly influencing patients' ability to sustain behavior changes, achieve metabolic targets, and prevent complications. Healthcare professionals, particularly nurses, should integrate structured family-centered strategies into routine care, fostering collaborative decision-making and enhancing long-term adherence to treatment plans.
Impact: A family-centered model can contribute to reducing health disparities and enhancing diabetes management outcomes globally. Future interventions should be designed to accommodate the unique needs of each family unit, ensuring equitable care that considers multimorbidity, ethnicity, and healthcare accessibility.

Reporting Method: We used Preferred Reporting Items for Systematic Reviews and Meta-Analyses.

No Patient or Public Contribution

Registration: PROSPERO registration number is: CRD42023402704

1. INTRODUCTION

Diabetes Mellitus, from now on referred to as diabetes, is a complex disease that affects 537 million adults (International Diabetes Federation, 2021). The global increase in diabetes prevalence can be explained by population aging and cultural and social changes conditioned by increasing urbanization (International Diabetes Federation, 2021).
Considered a top priority on global policy agendas, diabetes is responsible for a high number of premature deaths, disabilities, and for the increased need for medical care (American Diabetes

Association, 2022). The required resources to control diabetes and the severity of its complications impose a huge individual, social, and health systems burden.

The diabetes epidemic curves and the rising number of its complications have exposed the fragility of individual care (Rosland et al., 2015). In accordance with international recommendations, the need to identify effective strategies in diabetes management has come to be seen as imperative by healthcare professionals and decision-makers (International Diabetes Federation, 2021).

Family is considered the primary source of health information, and a fundamental pillar of all family members. Family influences individual health behavior, and the disease process affects everyone (Shajani & Snell, 2019). When a diagnosis of diabetes is made in a family member, all family members need to integrate new reorganization strategies to face this new reality (Kaakinen et al., 2018). Thus, the development and change of self-management behaviors that impact the person themselves are required, as well as those that involve the whole family (Elsayed et al., 2023).

Extensive research has been conducted on interventions developed with adults diagnosed with diabetes and the involvement of their families (Bennich et al., 2019; Cai & Hu, 2016). Thus, literature has highlighted family involvement in diabetes interventions and management as a determining factor for the success of these intervention with significant improvement of patient outcomes, and the maintenance of self-management behaviors (Elsayed et al., 2023; McEwen et al., 2019).

Several systematic reviews have gathered and assessed the available evidence on the effectiveness of diabetes family-focused interventions with adults, reporting different patient and family outcomes. However, the current evidence on family interventions remains fragmented, because it is unclear which interventions are most effective and how to replicate effective systematic interventions programs in different settings and/or social contexts.

In the preliminary search in the JBI database of Systematic reviews, PubMed, PROSPERO, and Cochrane Database of Systematic Reviews no umbrella review was identified on diabetes family-focused interventions.

2. THE REVIEW

The umbrella review is a method of review that is an overview of existing systematic reviews. This review compiled evidence on family-focused interventions with adults with diabetes from various systematic reviews and evaluated their effectiveness on patient and family outcomes. We hope these results can provide a source of support to health professionals and to policy makers in decision-making (Busebaia et al., 2023; Sutton et al., 2019).

3. AIM

The aim of this umbrella was to identify and to summarize the evidence on family-focused interventions with adults with diabetes, and to evaluate their effectiveness on patient and family outcomes. We also intended to identify the current guidelines and future priorities of family-focused interventions with adults with diabetes (Busebaia et al., 2023).

To address the overall aim, we formulated the following questions: (1) What family-focused interventions have been examined in published systematic reviews? (2) What effects do family-focused interventions have on outcomes in adults with diabetes? (3) What effects do family-focused interventions have on family member outcomes? (4) What are the optimal delivery characteristics of family-focused interventions? (5) Which theoretical foundations support the development of the interventions? (6) What family characteristics impact on intervention outcomes?

4. METHODS

This umbrella was conducted according to the Joanna Briggs Institute (JBI) methodology for umbrella reviews, and reported following the PRISMA Preferred reporting items for systematic reviews and meta-analyses (Aromataris et al., 2020; Moher et al., 2009). The review protocol for this umbrella was registered on PROSPERO.

4.1. Search methods

The search strategy aimed to identify published and unpublished systematic reviews. A three-step search was performed. An initial search was limited to PubMed, CINAHL, and Scielo databases, using the search terms "diabetes" OR "diabetic" AND "family" OR "families" AND "intervention" AND "systematic review". This search aimed to identify the indexed and free-text terms most frequently used in articles developed on this topic through the analysis of their titles, abstracts, and keywords of the studies. A second search was conducted using indexed search terms and keywords, adapted and individualized to each electronic database. A third search was developed using gray literature.

Published systematic reviews were searched in the following electronic data: MEDLINE ®, CINAHL®, Scopus ®, Cochrane Library, SciELO - Scientific Electronic Library Online, PsycINFO (access via EBSCOhost Web), and JBI Evidence Synthesis. The references of all studies selected for critical appraisal were searched for additional studies. The gray literature and unpublished studies were mapped using the databases: RCAAP (Scientific Open Access Repository of Portugal), and OpenGrey. The search strategy used for MEDLINE® is provided in *supplementary material* File 1.

4.2. Eligibility criteria

The study selection was guided by the following eligibility criteria:

i. Type of studies: systematic or narrative reviews that covered quantitative, qualitative, or mixed methods studies, internationally accepted; Systematic reviews with or without meta-analysis, using quantitative methodologies (randomized controlled trials, quasi-experimental, and pre-post design) or multi-methods/mixed methodologies (i.e., both quantitative and qualitative) and; grey literature (theses, unpublished studies and information produced by researchers on academic environment) was included. Professional guidelines were excluded.

ii. Type of interventions: interventions in which participation, supervision, or support of family members in diabetes management to accomplish behavioral, educational, or psychological changes was required. The person-centered interventions without family involvement were excluded.

iii. Type of participants: people diagnosed with diabetes aged 18 years and over and their family members. The definition of family member was not restricted to blood ties or legal definition, or as living in same household. Persons who were hospitalized, pregnant, or diagnosed with a mental disorder were excluded.

iv. Type of controls: systematic reviews that compared participants' outcomes of the intervention group to a control group, wait-list, or usual care participants' outcomes. Systematic reviews or narrative reviews that examined changes in the outcomes only in interventions group, without comparator (s) or control.

v. Type of outcomes: systematic reviews or narrative reviews that covered people with diabetes and families' outcomes: a) biological, b) behavioral/ knowledge, c) physiological.

vi. Types of contexts: included all contexts that reflected health and social care. No context limitations were applied, including settings, ethnic groups, and geographic locations.

vii. Language: Studies written in English, Portuguese, Spanish and French language.

viii. Revision period: Studies published and not published from 2013 to 2024.

4.3. Quality appraisal

Before inclusion in this umbrella review, the eligible studies were assessed by two independent researchers for methodological validity. The methodological validity assessment was performed by two researchers using a standardized Critical Appraisal Checklist for Systematic Reviews and Research Syntheses from Joanna Briggs Institute (Aromataris E et al., 2015). Any disagreement between the researchers was resolved through discussion or with the input of third researcher. Concerning the quality of each eligible review, a low-quality score of 4 was pre-established for inclusion in this review. The

minimum score criterion was defined in accordance with other studies that used this JBI instrument (Santos et al., 2019).
The quality score of each review was based on the following defined cut-off points: 0–3 very low-quality score; 4–6 low-quality score; 7–9 moderate-quality score; and 10–11 high-quality score.
Two researchers performed an overall assessment of the quality of quantitative findings using the Grading of Recommendations, Assessment, Development and Evaluation – GRADE (Guyatt et al., 2008). This quality assessment approach provides a system for rating quality of the evidence, and the strength of the recommendations. A four-point rating scale was used to rate the quality of the evidence: high, moderate, low, and very low. The quality of evidence of studies was classified according to the following criteria: risk of bias of primary, inconsistency, imprecision, indirectness, and publication bias. The Confidence in Evidence from Reviews of Qualitative research (GRADE-CERQual) was used to assess the confidence level in the evidence extracted of the qualitative reviews (Lewin et al., 2018). This instrument includes four dimensions: methodological limitations, relevance, coherence, and adequacy; the overall assessment of confidence was done using four levels: high, moderate, low or very low.
The heterogeneity between the reviews in terms of the characteristics of interventions, settings of each study, differences of outcomes assessed, and time points of the outcome assessment led to the creation of a narrative summary of findings concerning the CERQual qualitative assessment and GRADE results.

4.4. Data extraction and synthesis

All results were imported into Endnote X20® reference management software (Clarivate Analytics, PA, USA). After deleting duplicate references, two researchers independently screened all articles based on titles and abstracts. The discrepancies were solved through discussion, and if no consensus was reached, a third researcher was involved. The potentially relevant full texts were assessed by the same two authors to confirm if the studies were in accordance with inclusion criteria. Full-text studies that did not meet the inclusion criteria were excluded, and the reasons for exclusion were provided.
The information extracted from each systematic review included: i) author; ii) year; iii) review aim; iv) type of review; v) country; vi) review period; vii) databases used; viii) number of studies included; ix) study designs; x) target population; xi) exclusion criteria; xii) sample; xiii) intervention themes; xiv) interventions details and teaching methods; xv) intervention duration; xvi) settings; xvii) key outcomes; xviii) family' outcomes; xix) interventionists; xx) family definition; xxi) family involvement; xxii) quality/bias assessment; xxiii) specific theories or theoretical models; xxiv) follow-up; xxv) findings/ conclusions. This information was checked by another researcher and was described in supplementary material File 2.
Any disagreement between the researchers was resolved through discussion or with a third researcher. Authors of papers were contacted to request missing or additional data when needed.
Two researchers gathered and structured the data from the reviews included. Findings were organized using tables and by narrative synthesis according to the review aim and specific questions. The summary of findings is described, and includes the year of publication, authors, country title, method of analyses, number of included studies, and main results. A high level of detailed information for each systematic review is also described in this table.

5. RESULTS

The initial search strategy identified 4552 studies. After removing 431 duplicates, 4140 studies were screened by relevance of their titles and abstracts. The full-text of the remaining 19 studies were assessed for eligibility, of those 14 were excluded for different reasons. A total of 5 systematic reviews met the inclusion criteria and were included in this umbrella review.
The detailed information on screening process was presented through the adapted Preferred Reporting Items for Systematic Reviews and Meta Analyses flowchart in Figure 1 (Moher et al., 2009).

Figure 1. PRISMA flow diagram of study selection

5.1. Methodological Quality appraisal

The methodological quality assessment of all reviews was performed by two researchers using the JBI methodology (Table 1). Three reviews (18%) reported clear information on all criteria listed in JBI checklist (Baig et al., 2015; Thirsk & Schick-Makaroff, 2021; Zhang et al., 2022). Six of the 11 criteria (55%) were met by all reviews. The remaining five criteria (5,6,7,8,9) were not met or were rated as unclear due to lack of information. One review missed information in the critical appraisal process (Torenholt et al., 2014), and another did not provide clear information on this criteria (Pamungkas et al., 2017). The same reviews did not provide clear information in the methods used to minimize errors. One review reported unclear information on the likelihood of publication bias assessment (Torenholt et al., 2014). The minimum number of criteria was seven and the maximum was 11. No review was excluded on the basis of methodological quality criteria.

Table 1. JBI critical appraisal results of eligible systematic reviews

A GRADE assessment of quantitative outcomes pooled in this review led to the quality of the three reviews to be downgraded for: the variability of the interventions, the heterogeneous methodology, and unclear information on blinding randomized controlled trial designs (RCT), small sample sizes (n=10 to 83) or number not clear, and due to the tendency of studies to only publish positive results (Baig et al., 2015; Pamungkas et al., 2017; Torenholt et al., 2014). The score of one review was moderate-quality evidence based on values of heterogeneity assessment (Zhang et al., 2022).

Only one review described quality results (Thirsk & Schick-Makaroff, 2021). According to CERQual criteria, the review results based on confidence were scored as high confidence. This instrument assigned findings with minor concerns on methodological limitations, relevance, coherence, and adequacy. The inclusion of the original studies was based on their appraisal risk of bias assessed using the Critical Appraisal Skills Program qualitative checklist (Long et al., 2020). These six studies, although developed in USA, offered data from specific cultural groups defined by ethnicity, culture and traditions, socioeconomic status, and geography. The data extraction and synthesis were organized using imported concepts, mechanism, and outcomes that were based on descriptions from Medical Research Council framework for complex interventions and realist evaluation framework (O'Cathain et al., 2019). The quality appraisal is reported in *supplementary material File 3 and 4*.

5.2. Characteristics of included reviews

The year of publication of the five systematic reviews ranged from 2013 to 2024, and overall included a total of 89 original studies.

The most common study design was the randomized controlled trial (Baig et al., 2015; Pamungkas et al., 2017; Torenholt et al., 2014; Zhang et al., 2022). Other study designs reported were non-randomized trial, pilot study (Torenholt et al., 2014), experimental study (Baig et al., 2015), quasi-experimental, mixed methods (Pamungkas et al., 2017), qualitative, and exploratory designs (Thirsk & Schick-Makaroff, 2021).

The analysis methods used were the narrative synthesis (Baig et al., 2015; Pamungkas et al., 2017; Torenholt et al., 2014), the qualitative meta-synthesis (Thirsk & Schick-Makaroff, 2021), and meta-analysis (Zhang et al., 2022). The reviews were conducted in different continents and various countries, including China (Zhang et al., 2022), Canada (Thirsk & Schick-Makaroff, 2021), Thailand (Pamungkas et al., 2017), the USA (Baig et al., 2015), and Denmark (Torenholt et al., 2014), reflecting analyses of interventions influenced by cultural differences.

5.3. Characteristics of participants and contexts

The participants, according to the defined inclusion criteria, included individuals diagnosed with diabetes aged 18 or over. Regarding the type of diabetes, one study included only participants with type 2 diabetes (Thirsk & Schick-Makaroff, 2021), another included participants with both type 1 and type 2 diabetes (Torenholt et al., 2014; Zhang et al., 2022), while two studies did not provide details about the participants (Baig et al., 2015; Pamungkas et al., 2017).

Concerning intervention settings' details, the reviews included community health centers and sites, academic medical centers, churches, and Veterans' Administration hospitals. In addition, some

interventions considered differences in culture and socioeconomic conditions of the patients. Tailored approaches for minority, or economically disadvantaged families were evaluated in three of the five reviews (Baig et al., 2015; Thirsk & Schick-Makaroff, 2021; Zhang et al., 2022). One review highlighted the adaptation of interventions to cultural contexts, addressing factors such as local language, beliefs about the disease, traditional diet, exercise practices and culturally relevant learning methods (Torenholt et al., 2014).

5.4. Summary of key characteristics of family-focused interventions

The results of the general review allowed us to identify a variety of family-centered interventions (supplementary material File 2).

Among the reported characteristics of these interventions are their duration, the number of sessions included and the accompanying strategies employed. The duration of the interventions ranged from two hours (Pamungkas et al., 2017) to 12 months (Zhang et al., 2022). In the reviews that clearly specified the number of sessions, this ranged from three (Torenholt et al., 2014) to 18 (Zhang et al., 2022). Notably, only one review did not report on follow-up strategies (Thirsk & Schick-Makaroff, 2021), while the remaining four provided descriptions of these approaches. The remaining four reviews described these strategies; however, the results obtained were not clearly reported. Follow-up strategies were applied immediately after postintervention or up to a maximum period of 36 months (Baig et al., 2015) and included mailing, face-to-face, mixed face-to-face follow-up, and telephone or computer-based strategies.

The interventions involved a diverse range of healthcare professionals, including community health workers, promotors, medical teams, pharmacists, certified diabetes educators (CDEs), peer or lay leaders, dietitians (RDs) or nutritionists, psychologists or mental health providers, nurse practitioners, health educators, dentists, and researchers. However, two of the five reviews did not specify this information (Pamungkas et al., 2017; Torenholt et al., 2014).

5.5. Family Involvement in Interventions: Role and Definition

The role and definition of the family varied according to the studies, however, its integration in diabetes management has proven to be fundamental in adhering to therapeutic plans and optimizing clinical and psychosocial outcomes.

Families play a pivotal role in supporting adults with diabetes, offering emotional, practical, and social support that substantially enhances effective disease management and overall well-being. Despite this, the manner in which families are incorporated into interventions remains insufficiently addressed. Studies fail to provide detailed accounts of family involvement and offer only limited clarity regarding the conceptualization and definition of "family" within the context of their research.

The most common criterion for defining the concept of family primarily focused on blood relations, marital status, or cohabitation with the individual diagnosed with diabetes (Baig et al., 2015; Thirsk & Schick-Makaroff, 2021; Zhang et al., 2022). Broader definitions, including close friends or supportive individuals, were noted in some studies (Baig et al., 2015; Torenholt et al., 2014). The concept of family was not clear in one review (Pamungkas et al., 2017).

Regarding family involvement in the sessions, active participation by family members was emphasized as a key element in the study by Torenholt et al. (2014). In another review, the intervention explicitly included both the individual diagnosed with diabetes and a family member as the primary unit (Pamungkas et al., 2017). In contrast, two reviews indicated that family members were invited or encouraged to participate, but their involvement was optional (Baig et al., 2015; Thirsk & Schick-Makaroff, 2021). Details about the number of sessions involving family members was inconsistently reported. Notably, family participation was explicitly mentioned in only one review (Zhang et al., 2022).

Themes and strategies of interventions

The intervention themes were diverse and mostly focused on themes directed at the person with diabetes. Regarding the themes centered on individuals with diabetes, the following were addressed: diabetes-specific knowledge, diabetes management behaviors (e.g., dietary behaviors, healthy meals, physical

activities, blood glucose levels, medication adherence); psychosocial themes (anxiety, depression, stress, mood swings, stress management, perceived support, quality of life, effective day to day coping, communication and supporting skills); and how to avoid or oppose trigger that leads to negative behaviors. The interventions also focused on themes directed at family members, addressing several key aspects. Two reviews emphasized enhancing family members' diabetes-specific knowledge, particularly in managing the disease (Thirsk & Schick-Makaroff, 2021; Zhang et al., 2022). Other reviews highlighted the importance of improving relational dynamics and emotional connections, including listening skills, goal setting, problem-solving, behavior change, and teaching positive reinforcement techniques (Pamungkas et al., 2017; Torenholt et al., 2014). Additionally, interventions aimed to equip family members with skills to support dietary and exercise changes in the person with diabetes and provided strategies to manage stress related to familial and social relationships (Baig et al., 2015).

The interventions incorporated a variety of strategies designed to provide comprehensive support to adults with diabetes and their families. The use of individual format sessions was reported in one review (Pamungkas et al., 2017); however, this review, in addition to the remaining four reviews, also described other strategies, including: group sessions; individual sessions in association with group sessions, home visits, and celebratory events. The target population for each session was not clearly stated. The use of technology was highlighted in the review, including mobile communication, DVD technology, Bluetooth technology, tele-monitoring calls (Pamungkas et al., 2017), messages or video (Zhang et al., 2022), interactive voice response (IVR) to support blood glucose monitoring at home, and self-care support between primary care visits (Baig et al., 2015). In the study conducted by Pamungkas et al. (2017), participants were provided with various educational materials, including handouts, booklets, and pedometers.

The strategies aimed at family members encompassed a variety of approaches to enhance their involvement in supporting individuals with diabetes. These included active participation in activities such as physical activities, cooking, problem-solving, goal setting, and building self-efficacy. (Pamungkas et al., 2017; Torenholt et al., 2014). Family education played a significant role, focusing on providing strategies for stress relief, self-management practices, goal setting, problem-solving, identifying barriers to self-management behaviors, and optimizing environmental conditions (Pamungkas et al., 2017). Additionally, strategies targeted the improvement of positive reinforcement and listening skills (Torenholt et al., 2014), as well as motivational coaching (Baig et al., 2015). Other strategies included delivering notifications to family members through prerecorded support messages (Baig et al., 2015), email (Pamungkas et al., 2017), or telephone calls (Zhang et al., 2022). These notifications were used to inform family members of the patient's progress, enhance communication skills, and suggest self-management behaviors aligned with the patient's results. Furthermore, one review incorporated family-themed topics into educational sessions to deepen family involvement (Baig et al., 2015). In the study by Torenholt et al. (2014), additional strategies were emphasized, such as the development of family support plans, practical instructions on requesting assistance from family members, and integrating lifestyle changes into family routines.

5.6. Theoretical foundations

Specific theories, models, and theoretical frameworks that support intervention development, their strategies, and outcomes assessed were identified in three systematic reviews (Pamungkas et al., 2017; Torenholt et al., 2014; Zhang et al., 2022).These comprised the Social Learning Theory, Innovative Care for Chronic Conditions, Self-Regulatory Model of Illness Behavior, Social Action Theory, Social Cognitive Theory, and Empowerment or Health Belief Model. One review did not report this information, and another, although had mentioned the use of a theoretical framework, did not provide details (Baig et al., 2015; Thirsk & Schick-Makaroff, 2021).

5.7. Effectiveness of family- focused interventions

In all reviews, the family-focused interventions were associated with improvements in patients' outcomes, and three out of five reviews reported improvements in family outcomes (Baig et al., 2015;

Thirsk & Schick-Makaroff, 2021; Torenholt et al., 2014). Most studies evaluated the effectiveness of the interventions by comparing the results of the intervention group with a control group (Baig et al., 2015; Torenholt et al., 2014; Zhang et al., 2022). In these studies, the control group included usual care, participants with no instruction given, individual interventions, and wait-listed participants. One of five reviews explored the context and qualitative outcomes of different interventions reported in original studies (Thirsk & Schick-Makaroff, 2021).

The patient outcomes could be grouped into three categories: biological, behavioral/knowledge, and psychological. In terms of biological outcomes, all reviews reported improvements for HbA1c levels. In one review (Zhang et al., 2022), statistically significant decrease in HbA1c levels (%), $p < 0.01$, were described after intervention. In the same study, a statistically significant improvement in fasting glucose, $p < 0.01$ was also demonstrated; improvement in body mass index (BMI) was reported in three reviews (Baig et al., 2015; Pamungkas et al., 2017; Zhang et al., 2022); however, only one review reported a statistically significant improvement (Zhang et al., 2022); the same three reviews reported improvements in blood pressure. In the study by Zhang et al. (2022), the difference was statistically significant, $p = 0.01$. A significant weight improvement was reported in one review (Baig et al., 2015). An improvement in lipid profile was reported in three reviews (Baig et al., 2015; Pamungkas et al., 2017; Zhang et al., 2022), but only one reported significant improvement after intervention (Pamungkas et al., 2017).

Concerning the behavioral/knowledge outcomes reported: diabetes self-management behaviors showed a statistically significant improvement in the intervention group ($p < 0.01$) when compared with the control group (Zhang et al., 2022). Likewise, two reviews described significant effects on this outcome (Pamungkas et al., 2017; Torenholt et al., 2014). The diabetes knowledge was assessed in three reviews (Thirsk & Schick-Makaroff, 2021; Torenholt et al., 2014; Zhang et al., 2022) but only one (Zhang et al., 2022) reported values that demonstrated statistically significant improvements after intervention ($p < 0.01$). Improvements in diabetes medication adherence were reported in three reviews (Baig et al., 2015; Pamungkas et al., 2017; Zhang et al., 2022), and a statistically significant difference ($p < 0.01$) was reported in one of them (Zhang et al., 2022). Self-efficacy improvement was statistically significant ($p < 0.01$) in eight of the original studies included in the review developed by Zhang et al. (2022).

The psychological outcomes reported included: a statistically significant diabetes distress decrease ($p< 0.01$) when compared with the control group (Zhang et al., 2022); overall reduction in depression symptoms, although not significant in two reviews (Baig et al., 2015; Zhang et al., 2022); improvements were also reported in quality of life and in the psychological well-being, although not statistically significant (Baig et al., 2015).

In addition to the outcomes already mentioned one review described a significant decrease in the healthcare utilization (emergency room utilization and number of hospitalizations) and in the costs of the interventions (Baig et al., 2015).

Regarding family health gains following the intervention, reported outcomes comprised biological outcomes in two reviews (Baig et al., 2015; Torenholt et al., 2014); diabetes-related knowledge in one review (Thirsk & Schick-Makaroff, 2021); and family engagement rates in two reviews (Baig et al., 2015; Thirsk & Schick-Makaroff, 2021). Family-specific measures, such as family involvement, supportive behaviors, and family functioning, were reported in all reviews.

Family support improvement was described in all reviews; however, improvement values were not clearly detailed in the results. Two reviews explored the two dimensions of family support (positive/supportive and negative/obstructive). One of these reviews reported a statistically significant improvement in the positive dimension of family support after the intervention ($p < 0.01$), as well as a reduction in the negative dimension, although the latter was not statistically significant (Zhang et al., 2022). Furthermore, in one review, family members were observed to become more supportive of the patient, particularly in facilitating lifestyle changes (Baig et al., 2015). These authors also noted higher engagement rates in interventions among patients whose families were involved compared to those whose families were not ($p = 0.008$). Similarly, patients whose family were present regularly checked his/her blood pressure ($p=0.002$) and had less probability to report high glycose levels ($p=0.002$). Results are reported in Table 2

In terms of biological outcomes, significant changes were reported for BMI (– 0.25 kg/m2) in one review (Baig et al., 2015), while other measures, including waist circumference, blood pressure, and fruit and vegetable consumption showed no significant changes. Additionally, one review reported statistically significant improvements in family blood sugar levels (Torenholt et al., 2014). Significant improvement in diabetes knowledge among family members were also highlighted in one review (Baig et al., 2015).

Table 2. Summary of findings of included systematic reviews

6. DISCUSSION

Health professionals and researchers worldwide are increasingly focused in the development of interventions for adults diagnosed with diabetes and their family that are meant to be more effective (International Diabetes Federation, 2021). In accordance with the international standards of medical care in diabetes, all people with diabetes should participate in diabetes education and be supported to improve their diabetes-specific knowledge and diabetes self-management skills (Elsayed et al., 2023).To achieve diabetes treatment goals, it is necessary to establish positive health behaviors and maintain well-being. In this regard, the importance of family involvement in the management of diabetes has been emphasized in literature (Elsayed et al., 2023).

The extensive number of systematic reviews in this field justified the development of this review. All included reviews demonstrated a clear association between family involvement and the improvement of patient and family outcomes. These outcomes included the improvement of positive family supportive behaviors for diabetes self-management activities and patient lifestyle changes, regardless of the interventions' characteristics or setting. Similar findings were observed in other studies involving people with long-term conditions, namely diabetes, further reinforcing international recommendations (International Diabetes Federation, 2021; Smith et al., 2020; Zupa et al., 2021). However, like other research in the field, this umbrella review identified a need for continued efforts to better understand how family-focused interventions contribute to health improvements for both the diagnosed individual and their family members (Smith et al., 2020).

A recurring limitation across the reviews was the heterogenous information reported or in some cases, the lack of clarity in how the information was presented, namely on family definition (Busebaia et al., 2023). Some reviews restricted family inclusion to biological or legal relationships, while others adopted broader definition of family (Baig et al., 2015; Torenholt et al., 2014). Adopting a restrictive concept of the family can compromise the participation of people with diabetes and their families in interventions, and does not reflect the evolving concept of family, which recognizes that family members are "who its members say they are" Wright & Leahey, 2013, p.55). Health professionals and researchers are encouraged to adopt a dynamic and inclusive understanding of the concept of family, allowing the diagnosed person to choose their preferred support people (Kaltman et al., 2015).

Diabetes management can be complex, usually occurring in a family context, and requires adjustments to daily activities that affect both people with diabetes and their families (Elsayed et al., 2023; International Diabetes Federation, 2021). Factors such as socioeconomic status, cultural beliefs, family dynamics, and access to healthcare resources play a significant role and vary across cultural contexts (Soares et al., 2024) This underlines the importance of multidimensional diabetes care and culturally sensitive approaches, recognizing that family structures and the caregiving roles differ globally. Additionally, caregiving discrepancies often stem from traditional gender roles, which conventionally place greater responsibility on women for managing households, raising children, and caring for sick family members, while men are socialized to prioritize professional careers. This unequal division of responsibilities can disproportionately burden certain family members, impeding a balanced approach to diabetes management (Ciarambino et al., 2022). Thus, understanding these dynamics is essential for designing interventions that are both equitable and effective.

Important findings that emerged from this umbrella review, and that support the evidence already produced in the area of diabetes, was the strong association between diabetes outcomes and health

inequalities, particularly regarding social, economic, political, cultural, and environmental conditions in which people with diabetes live, an issue emphasized by WHO (World Health Organization, 2023). Three out of the five reviews assessed interventions tailored to cultural and minority groups and that were associated with positive outcomes (Baig et al., 2015; Thirsk & Schick-Makaroff, 2021; Torenholt et al., 2014). For example, interventions conducted in Asian regions confirmed greater reductions in hemoglobin A1c, which could be explained by the influence of traditional culture and family values (Zhang et al., 2022).. These results were supported by other studies developed in this region (Azami et al., 2018; Wichit et al., 2017). Diabetes outcomes, rather than being associated with the personal characteristics of patients and their families, are strongly associated with broader social determinants, such as social and economic environments and healthcare access (Golden et al., 2012; World Health Organization, 2023). Consequently, environments with a lack of healthy food stores, places to exercise, and with an increase in psychosocial stressors related to crime or inadequate social cohesion were associated with poor health outcomes (Soares et al., 2024; World Health Organization, 2019).

Regarding the outcomes described in the included studies, some authors suggested that supplementing individual outcomes with family outcomes, such as family dynamics, could provide health professionals and researchers with a more holistic understanding of family functioning, potentially leading to greater health benefits for all members involved (Torenholt et al., 2014). However, the family outcomes following interventions were frequently reported. Although three reviews included family outcomes, like biological, family-specific dynamics, and diabetes-specific knowledge, the improvements observed were not consistently statistically significant (Pamungkas et al., 2017; Torenholt et al., 2014; Zhang et al., 2022).

Family diabetes-specific knowledge is regarded as a critical factor in fostering positive and supportive family dynamics by people with diabetes (Thirsk & Schick-Makaroff, 2021). However, the literature highlighted that possessing this knowledge does not always translate into supportive behavior toward the diagnosed individual. In some cases, family members may even engage in unsupportive or sabotaging actions (Mayberry et al., 2019; Mayberry & Osborn, 2014). These family behaviors are justified by the same authors as the family's lack of motivation to make lifestyle changes, and/or to support patients with these activities.

The literature mostly focused on the importance of family positive support and paid less attention to the negative family support dimension, including family conflicts, diversity of relationship patterns, and family's cultural beliefs, and their negative impact on disease management (Mayberry et al., 2019). In addition, other elements should be considered in relation to family support, such as the importance that a person with diabetes attaches to their independence (Thirsk & Schick-Makaroff, 2021). Some patients did not place value on the role and support that family could provide in diabetes management, choosing as an alternative a more independent lifestyle. Moreover, some patients believe it is not fair to demand from family members to make changes because of the disease challenges (Bennich et al., 2019; Thirsk & Schick-Makaroff, 2021). Recognizing the importance of support, even just the emotional support, means that the diagnosed person has to balance their independence with interdependence, not only with family, but also with social and community support, whose value is undeniable (Baig et al., 2015).

This review, in accordance with recent diabetes standards of care, highlighted the need for interventions that promote meaningful family engagement and address the health determinants and multimorbidity patterns influenced by cultural and socioeconomic factors. Additionally, the importance of tailoring interventions to local contexts rather than adopting standardized global solutions was emphasized (Bosch-Capblanch et al., 2007; Jordan et al., 2018).

Researchers should therefore be encouraged to provide more detailed descriptions of interventions, specifically addressing the strategies employed to enhance family support and how these are implemented and interact during sessions. The lack of such information hinders future researchers from replicating these strategies and evaluating their effectiveness. Furthermore, it limits the ability to identify which characteristics of family members and attributes of the interventions were deemed optimal for achieving greater health gains.

Building on this, the integration of effective communication within delivery systems and the collaboration of a dynamic team—including health professionals, patients, and family members—has been increasingly recognized as essential for optimizing diabetes management (Elsayed et al., 2023).

In order to improve communication between people with diabetes and their families and health professionals, the results of the five reviews support the use of interactive strategies and their effectiveness on outcomes. These strategies comprise motivational interviewing, behavioral activation, and didactic and participatory learning. In the umbrella review findings, the use of virtual environments was also reported, which has rapidly changed from traditional medical learning methodologies, and included mobile communication, DVD technology, Bluetooth technology, and tele-monitoring calls (Baig et al., 2015; Pamungkas et al., 2017; Singh et al., 2020; Zhang et al., 2022). The use of these strategies in diabetes education interventions, as well as digital coaching, and digital self-management interventions, were also emphasized in the standards of care in diabetes as being effective in removing some barriers to people's participation in interventions (Elsayed et al., 2023). These barriers included the busy lives of members of family, economic demands, transportation and geographics costs, and multiple appointments that patients have to attend (Thirsk & Schick-Makaroff, 2021). Thus, the effectiveness of these strategies was stated in other studies in the field of diabetes, with improvements in several outcomes (e.g., waist circumference, glycated hemoglobin, stress, depressive symptoms, and diabetes-specific knowledge) in different settings (Azami et al., 2018; Bender et al., 2017; McEwen et al., 2019).

Despite these advances, gaps remain particularly in understanding the specific attributes of family-focused interventions that lead to better outcomes. Researchers must adopt a holistic approach to family dynamics and diabetes care, incorporating theoretical models and addressing barriers to self-management (Alshakhs et al., 2022; Elsayed et al., 2023; Wichit et al., 2017).

Health professionals and health political decision-makers should find new forms of multi-stakeholders to support making healthy life choices and empower people with diabetes by making the healthiest choice the easiest choice through the creation and development of health environments and improvement of their health literacy (World Health Organization, 2019, 2023). More than improving patients and families knowledge, new approaches should include their meaningful engagement, and empower both with new tools that will allow them to make informed health decisions, with decision-support from a team of healthcare professionals whose practice priority is high-quality care and evidenced-based standards (Elsayed et al., 2023). Patients and families, by being included in the care team, can contribute with their lived experiences, which can help professionals to understand and manage all conditions that affect their health choices and disease outcomes (World Health Organization, 2019, 2023). Co-creation of interventions with patients and families, informed by lived experiences, can provide insights for addressing the complex challenges of diabetes management and promoting health equity (World Health Organization, 2019, 2023).

To improve diabetes care, it is essential not only to evaluate the effectiveness of interventions but also to understand the relationships between individuals with diabetes and their families, the theoretical frameworks underpinning interventions, their content, and the outcomes assessed. This approach provides valuable insights for refining future research and interventions (Varghese et al., 2020). The integration of robust theoretical foundations and insights from prior research enhances the design of behavior-changing interventions and ensures greater precision in defining and measuring constructs (Rejeski & Fanning, 2019; Smith et al., 2020). However, many reviews acknowledged the use of theoretical models but lacked detailed reporting on their foundations, particularly regarding family and social dimensions, health determinants, and barriers or motivators to self-management (Baig et al., 2015).

Addressing these gaps, this umbrella review assessed the effectiveness of interventions involving adults and their families, employing rigorous methodologies to ensure reliability. Nonetheless, limitations such as heterogeneity in intervention details, insufficient reporting of clinical and sociodemographic characteristics, and limited consideration of cultural and socioeconomic diversity were noted, hindering broader applicability.

Despite these challenges, the review emphasized the need to consider the family and the individual with diabetes as a single unit of care, moving beyond the view of family as merely a means to improve patient

outcomes. Future interventions should be tailored to foster meaningful engagement, addressing health determinants and multimorbidity patterns shaped by ethnicity, culture, socioeconomic status, and access to healthcare. These insights are critical for advancing both research and policy development in diabetes care.

6.1. Strengths and Limitations

This umbrella review focused on the effectiveness of family-focused interventions for adults with diabetes, employing a comprehensive search strategy to identify the most relevant systematic reviews in this field. To minimize the risk of bias and ensure the inclusion of studies with robust methodologies, critical appraisal tools were applied to all reviews. A rigorous data extraction and synthesis process was conducted, providing a structured overview of the interventions.

However, several limitations must be acknowledged. One of the main challenges was the heterogeneity in the description of the interventions, which hindered direct comparisons regarding their effectiveness. The lack of standardized reporting limited the ability to assess specific components of the interventions, including variations in their implementation, duration, and intensity. Additionally, the diversity of assessed outcomes, combined with differences in cultural and contextual settings, further complicated comparisons between studies. Despite the limited descriptions, our analysis indicated notable differences in these aspects, reinforcing the need for greater transparency and detail in future research.

Moreover, insufficient information on participants' clinical and sociodemographic characteristics (e.g., age, duration of diabetes diagnosis) was observed. The limited reporting of factors such as cultural, linguistic, social, and economic conditions made it difficult to determine the broader applicability and transferability of these interventions across different populations. Future research should emphasize more comprehensive and standardized descriptions of interventions and participant characteristics to enhance comparability and facilitate the development of tailored, evidence-based family-centered strategies in diabetes management.

7. CONCLUSION

The evidence presented in this umbrella review demonstrated that diabetes family-focused interventions with adults are an effective strategy to improve patients' and families' outcomes and consequently promote their health.

Family members, whose involvement in interventions had benefited their own health, should be considered as a unit of care with the person with diabetes, and not a merely strategy to improve the patient's outcomes.

Diabetes family-focused interventions based on education, and behavioral changes for the person with diabetes and their family, and in which the family active involvement is essential, were effective in promoting the family members' positive support in diabetes self-management activities, and in the adoption of healthy lifestyles.

Future tailored interventions should be developed and assessed regarding health disparities and minorities, as well as diversity in culture, language, and social and economic conditions.

People with diabetes, and their families, with their lived experience and resources, empowered with health knowledge and skills, are better equipped to contribute to policy planning, healthcare services, and systemic diabetes governance decisions, regionally and nationally.

8. IMPLICATIONS FOR PRACTICE

The findings of this umbrella review reinforce the critical role of family-centered interventions in enhancing diabetes management and improving health outcomes for both individuals with diabetes and their families. Given the demonstrated benefits in glycemic control, adherence to self-management behaviors, and psychological well-being, healthcare professionals, particularly nurses, should integrate family involvement into routine diabetes care.

However, the lack of standardized intervention descriptions and the diversity of assessed outcomes highlight the need for more structured, evidence-based approaches. To enhance the effectiveness and comparability of interventions, future programs should adopt clear frameworks, ensuring a systematic and tailored approach to family engagement.

Healthcare professionals should also prioritize **personalized care,** recognizing that social, cultural, and economic contexts influence family dynamics and self-management capacities. Family-centered education should move beyond general diabetes knowledge to include tailored strategies that empower families to provide meaningful support while respecting the autonomy of the individual.

Finally, policymakers should recognize family involvement as a **key component of diabetes care policies**, supporting the development of structured programs that integrate family-centered strategies into healthcare systems. Future research should focus on refining and evaluating these interventions, ensuring that they are adaptable across different healthcare settings and responsive to the unique needs of diverse populations.

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Figure 1. PRISMA flow diagram of study selection

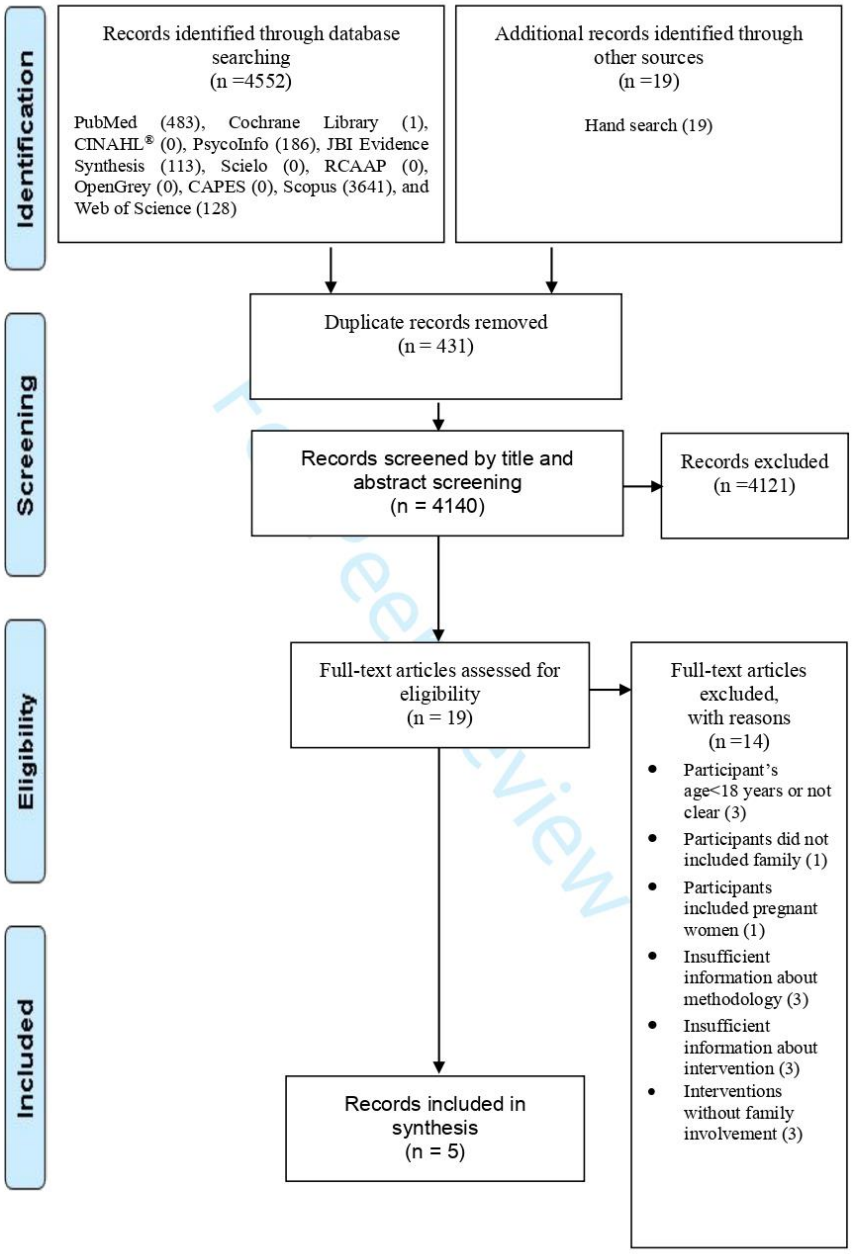

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Table 1. JBI critical appraisal results of eligible systematic reviews

Authors	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10	Q11	Quality
Zhang et al., 2022	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	High
Thirsk & Schick-Makaroff, 2021	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	High
Pagmungkas et al., 2017	Y	Y	Y	Y	Y	U	U	U	Y	Y	Y	Moderate
Baig et al., 2015	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	High
Torenholt et al., 2013	Y	Y	Y	Y	U	N	U	Y	U	Y	Y	Moderate

Y=Yes, N=No, U=Unclear.
JBI critical appraisal checklist for systematic reviews and research syntheses: Q1= Is the review question clearly and explicitly stated? Q2= Were the inclusion criteria appropriate for the review question? Q3=Was the search strategy appropriate? Q4=Were the sources and resources used to search for studies adequate? Q5=Were the criteria for appraising studies appropriate? Q6=Was critical appraisal conducted by two or more reviewers independently? Q7=Were there methods to minimize errors in data extraction? Q8=Were the methods used to combine studies appropriate? Q9=Was the likelihood of publication bias assessed? Q10= Were recommendations for policy and/or practice supported by the reported data? Q11=Were the specific directives for new research appropriate?
Quality scores: 0-3 =very low-quality score; 4-6=low-quality score; 7-9=moderate-quality score; 10-11=high-quality score.

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Table 2. Summary of findings of included systematic reviews

Authors (Year)	Appraisal instruments	Outcomes assessed	Main results	Strategies and recommendations	Conclusions and implications for research and practice
Zhang et al., 2022	Cochrane Collaboration Risk of Bias Assessment Tool: Risk of bias tool. Risk of Bias: The overall risk of bias in the included studies was relatively low. Sensitivity analyses were conducted to analyze heterogeneity Results present moderate heterogeneity (I^2 = 61.1%) combined with better quality of evidence. Body weight, by removing one study I^2 decreased. Diabetes self-management did not find any potential heterogeneity. Diabetes knowledge: subgroup analyses did not demonstrate any potential heterogeneity. Diabetes adherence to medication: Sensitivity analyses and subgroup analyses were not conducted because of insufficient studies.	- Glycosylated hemoglobin levels - BMI - Blood lipid - Distress - Family support - Depression - Diabetes self-care (diabetes self-management, diabetes adherence to medication)	Post-intervention HbA1c levels (%): significant decreasing (WMD = −0.48, CI = −0.69 to −0.28, z = −4.629, p < .01, I^2= 61.1%). BMI: significantly improved (WMD = −0.42, CI = −0.67 to −0.17, z = −3.305, p <.01 I^2=44.8%). DBP: significantly improved (WMD = −1.37, CI = −2.42 to −0.32, z = −2.559, p = .01, I^2 = 0%). Fasting glucose significantly improved (SMD = −0.19, CI = −0.32 to −0.07, z = −2.966, p <.01 I^2=12,7%). Blood lipids and body weight: did not change significantly. Seven studies assessed diabetes self-management: improvement compared to the control group. (SMD = 1.07, CI = 0.48 to 1.65, z = 3.554, p <.01 I^2=90.1%). Seven studies assessed diabetes knowledge: significantly improved (SMD = 0.82, CI = 0.47 to 1.17, z = 4.609, p <0.01, I^2 = 82.5%). Two studies assessed adherence to diabetes medication: Significant difference between IG and CG (WMD = 0.82, CI = 0.47 to 1.17, z = 4.609, p < 0.01, I^2 = 82.5%). Eight studies assessed self-efficacy: Significant improvement (SMD = 0.50, CI = 0.13 to 0.88, z = 2.623, p < 0.01, I^2 = 85.5%).	Family-based intervention mainly based on the social cognitive, self-efficacy, empowerment or health belief model. Strategies highlighted were problem identification and resolution with family members' participation (family members took active roles). Supportive approaches such as motivational interviewing and empowerment are also reported as effective strategies. The integration of home visits is a strategy recommended for diabetes management.	Family-based interventions had a significant advantage over the control group, especially in Asian settings. Family-based intervention should consider the diversity in culture, language, and religion of nations in terms of life habits. Family interventions for minority or economically disadvantaged families should be culturally tailored. It was recommended to integrate home visits into diabetes management. Family-based intervention: after intervention, HbA1c levels (%) reduced by 0,48%. This result was more successful in decreasing HbA1c in Asian regions Studies based on education, behavioral changes, and problem - solving were beneficial for glycemic control in adults with diabetes. Outcomes were not different, whether it used mobile devices or whether family members participated in the intervention completely. Meta-analysis provided more evidence that family-based intervention could improve other diabetes control indicators (BMI, blood pressure and fasting glucose), diabetes self-care, psychological outcomes and positive family support for patients with diabetes with respect

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	Diabetes self-efficacy: Sensitivity and subgroup analyses did not demonstrate any potential heterogeneity Family support: evidence of substantial heterogeneity ($I2 = 95.9\%$). Sensitivity analyses were conducted by removing studies one by one, and heterogeneity was decreased when one study was removed. Positive and negative dimensions of family support: Sensitivity analyses demonstrated that when one study was removed, the heterogeneity was decreased		Three studies reported on diabetes distress: significant decrease compared with CG (SMD = −0.46, CI = −0.70 to −0.22, z = −3.770, p< 0.01, I^2 = 37,0%). Two studies measure depression in diabetes patients: an overall reduction, but this was not significant (CI = −0.81 to −0.25, z = −1.028, $p = 0.30$, I^2 = 9.0%). Three studies measure family support: trivial but not significant effect in improving family support (SMD = 0.944, CI = −0.52 to 2.41, z = 1.260, $p = 0.21$). Positive and negative dimensions of family support: significant improvement in positive dimension (WMD = 3.71, CI = 2.59 to 4.82, z = 6.52, p < 0 outcomes were not different whether it used mobile devices or whether family members participated in the intervention completely. .01, $I^2 = 41.5\%$). Decrease in negative dimension but not significant (WMD = −0.82, CI = −2.82 to −1.18, $I^2 = 78.4\%$)		to self-management and lifestyle changes. Meta-analysis showed that family-based intervention is statistically significant in improving positive family support but not in decreasing negative family support. Family members' supportive behaviors or appreciative words may lead to improvement in health behaviors for adults with diabetes. Diversity was identified in family-based intervention characteristics, and it made it difficult to synthesize results with low statistical heterogeneity.
Thirsk & Schick-Makarof,2021	Critical Appraisal Skills Program qualitative checklist. No studies were excluded based on their appraisal. Constant comparison of intra-study concepts (reciprocal translation)	- Diabetes-specific knowledge - Diabetes management (diet, exercise, and medication - Diabetes self-care - Family's diabetes-specific knowledge	Improvement of diabetes management for the patient (specifically managing diet, exercise, and medication). The outcomes were not always explicitly stated and thus were extracted from the background, findings, and discussion sections.	Culturally tailored family-based interventions Behavioral tailored intervention for Latinos (using motivational interviewing and behavioral activation) Interventions include home visits, educational sessions, celebratory events, diabetes, and family curriculum.	Family interventions focused on education about diabetes management were focused on attributing the problem to a knowledge deficit and neglected other powerful mechanisms, such as the social or structural determinants of health and the intersection of other factors in the participant groups. Scarcity of resources had implications for family interventions, specifically the ability of patients and

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	Data extraction and synthesis were organized using the imported concepts of context, mechanism, and intervention outcomes. The concepts were based on descriptions from the Medical Research Council framework for complex interventions and realist evaluation framework			Strategies for increasing family member's knowledge as a significant mechanism for improving diabetes management	family members to participate in interventions. Mostly participants had busy work and family lives, could not financially afford to miss work, leaving limited time to attend interventions. However, there is inconsistent evidence about how and when family members should be involved, the inclusion of family members (culturally tailored and multigenerational) is emphasized. Patients consider it important to decide how and when the families are included and also to have individual time as well. Behavioral and biological outcomes should be assessed for both patients and family members. In the context of low resources, family and friends become important sources of material and psychosocial support. The development of family interventions should take into account the social determinants of health.
Pagmunkas et al., 2017	The inclusion criteria were based on JBI and PICO format (Participant-Intervention-Comparison-Outcomes). The review was limited by publication bias because positive findings tend to be published more frequently	- BMI - HbA1c/ blood glucose level - Blood pressure - Cholesterol level - Glycemic control - Medication adherence - Blood glucose - Monitoring - Diet and exercise changes - Psychological well-being - Self-efficacy - Family involvement - Social support	Significant effect on health outcomes: - self-management behaviors (diet, physical activity, blood glucose monitoring, foot infection and medication adherence). - physiological outcomes. - self-efficacy. - Clinical outcomes (HbA1c/blood glucose level, blood pressure, BMI status, and lipid profile).	DSME with combination of didactic teaching and interactive or participatory learning approaches. Strategies include a collaborative approach (mixed methods of teaching and family support involvement). Combination of didactic methods with participatory learning, goal setting, action planning, and problem-solving.	Regardless of the setting, the effectiveness of communication and supporting skills are important in influencing diabetes management behaviors. Patients with family member involvement (informal caregiver) in diabetes management had a higher rate of engagement. They were more likely to decrease blood glucose levels and to regularly check their blood glucose as well. Social support is a fundamental approach to sustaining self-

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	than null findings. Was decided to describe the results in a narrative form rather than as a meta-analysis because the authors did not have access to primary data and the variability in study design did not allow us to pool data. Therefore, the effect size of each study outcome was not described.			In the short-term interventions, strategies conducted using several strategies (including weekly telephone follow-ups, face-to-face follow-ups, negotiating, and discussing to design the goals and action plan and modify the goals and action plan) were more effective in improving health outcomes. Follow up methods	management behaviors and overcoming barriers among patients with diabetes. Patient who receives support is capable of getting advice when coping with difficulties and improving positive communication for diabetes care. The combination of didactic with other methods positively impacted health outcomes. Studies lacked information about how family members provided support for diabetes self-management behaviors, how they interacted in the program, or what family outcomes should be addressed in the intervention. Heterogeneous methods, strategies, populations, settings, and outcomes made it difficult to compare the effect size of each study. Further studies are needed to provide details of DSME in the intervention and compare the health outcomes with and without family involvement in DSME programs.
Baig et al., 2015	PRISMA guidelines. Each study was given a quality score by two members of the research team using an adapted questionnaire based on the Downs and	- HbA1c - Blood pressure - Weight - Lipid profiles - BMI - Psychosocial outcomes (depressive symptoms, diabetes distress, quality of life, self-efficacy,	Significant improvement of HbA1c and weight. Improvement of blood pressure, lipid profiles, and BMI. Improvements in psychosocial outcomes (depression, diabetes distress, quality of life, and self-efficacy).	Interventions group based or one-to-one individualized counseling. Interventions include home visits. Interventions including technology (mobile communication technology to support serum blood glucose	Most disease-management activities for many adults occur within the family environment; therefore, involving families in diabetes self-care interventions may be a key mechanism to improving diabetes outcomes for patients. Studies should compare similar interventions both with and without a family

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	Black guidelines (27-point scale: 0 worst, 27 best). Studies scored between 10-24,5, with a mean score of 18. Of the 27 criteria composing the quality score, the studies we reviewed scored the lowest in the following categories: attempt to blind the study subjects, attempt to blind those measuring the main outcomes, reporting of adverse events, using a representative sample, and reporting of sample-size calculation.	and perceived social support) - Family members' outcomes (diet, BMI, diabetes, waist circumference, blood pressure, and fruit and vegetables)	Improvements in diabetes self-management behaviors (diabetes-specific knowledge, dietary habits, physical activity, patients' blood glucose monitoring, medication adherence) and self-care behaviors. Emergency room visits: significant decrease. Family members' outcomes: significant changes in family member BMI (–0.25 kg/m2) and diabetes knowledge from baseline to post-intervention. No significant changes in waist circumference, blood pressure, and fruit and vegetable consumption.	monitoring, tele-transmission for home glucose, and interactive voice response).	component to truly assess the impact of including family on patient outcomes. The involvement of the family members and integration of families into the interventions varied widely across studies. Most studies did not describe a theoretical basis for family involvement or report on the extent of family involvement. Studies lacked details on the content designed for family members, how family members interacted in the class, and what family outcomes the interventions were targeting. Most studies lacked family involvement (family attendance or participation rates in the intervention, which was the concept of family adopted by the authors). The importance of the inclusion of family in diabetes self-care is empathized in patients from racial/ethnic minority populations. Culturally tailoring educational programs is recommended. The prevalence of diabetes among older adult populations increases the importance of involving family members and caregivers in interventions (for providing older patients with instrumental and social support related to their diabetes management). The role of gender in family-based interventions should be considered, and an assessment of cost should be included.
Torenholt et al., 2014	Studies lacked information on methodology	- Biological (blood sugar levels, HbA1c	Decline in HbA1c levels (IG compared with CG), but only one study one study	Group session	The number of studies with statistically significant results in family interventions

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	and intervention development details. Authors stated that reporting quality would be facilitated by consistently using the Consolidated Standard of Reporting Trials (CONSORT) statement and checklist.	- Lifestyle behaviors (weight, diet, and exercise) - Behavioral (attitudes about diabetes and perceived family support) - Knowledge - Family-specific outcomes (involvement, support, and functioning) - Family outcomes: blood sugar	demonstrated a significantly greater decline. Larger improvement in diet in the control group compared with the intervention group. One study reported statistically significant improvement in diet, illness perceptions, psychosocial well-being, and family support (at 6 months compared with the control group) One study found significantly better diabetes knowledge, improved attitudes about diabetes, and increased perceived family support (at 6 months compared with the control group).	Combined group sessions and individual sessions Strategies that emphasized active participation in physical activity, cooking, active problem-solving, goal setting and building self-efficacy.	targeting adults with diabetes is limited. Studies lacked intervention details, and it prevented a clear understanding of the methodology and the interventions' replication. The originally included studies were inconsistent with regard to the theoretical framework, intervention themes, and measured outcomes. Psychosocial and family dimensions seem sensitive to family-based interventions. Thus, from development to evaluation, the family dimension needs to be included to prove the specific effect of family interventions. Theory is important for effective interventions, and multifaceted interventions would benefit from a sound theoretical framework about the family. A theoretical framework appropriate to a family focus would help define intervention themes and outcome measures. Future family interventions for diabetes should address the family dimension more systematically and consistently. Conceptualizing the family as merely an aspect of social support and themes is overly simplistic. The value of addressing the family as a whole was generally overlooked. Family definition and patterns vary according to the culture, and it is defined by the context in which it exists. Family should make up the central unit of the interventions, and this dimension should be clearly reflected

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					throughout the intervention design. Individual outcome measures should be complemented with measures that include family dynamics and family members.

BMI: body mass index; HbA1c levels: glycosylated hemoglobin levels; WMD: weighted mean difference; DBP: diastolic blood pressure; IG: intervention group; CG: control group; CI: confidence intervals; SMD: standardized mean difference; JBI: Joanna Briggs Institute; DSME: Diabetes Self-Management Education

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Table 3. Summary of findings of interventions of included systematic reviews

Author/ year	Study design	Intervention	Instruments	Outcomes assessed	Domains of health literacy assessed	Results
Jiang et al. 2024	Pilot study design	Programme (C2C)	- Instrumentos:demographic questionnaires and evaluation questionnaires design by study researcher	knowledge and skills development, self-care ability, trainer engagement and training content	Not reported	Results showed that their caregiving knowledge, skills and selfcare ability were improved and the positive effects were maintained above baseline over the course of C2C and at 2-month follow-up Participants gained significant support from other caregivers and healthcare professionals
Mousaei et al., 2023	Quasi-experimental study	Family-centered empowerment model (FCEM)	- Demographic questionnaire and Zarit caregiver burden inventory caregiver burden inventory was designed to specify the, including 22 questions about the burden imposed by a caring a patient on the caregiver and the responses are based on Likert - scale (never = 0, rarely = 1, sometimes = 2, often = 3, and always = 4).	Level of care burden	Not reported	Intervention was effective in the changes of care burden scores ($p < 0.036$) and the interaction between time and treatment was not significant ($p < 0.053$). No statistically significant difference between the two groups (intervention and control) in terms of the care burden mean scores ($p < 0.225$)
Laine et al., 2021	Parallel mixed methods study design	Web-based psychoeducation course	- Assessment of participants activity on the learning platform (caregivers' log-ins for each module were automatically recorded on the learning platform). - Number of caregivers visiting every module and the number of finalized module tasks (calculated manually) - Written feedback about course and the website were asked to participants - Sociodemographic Information	Caregivers' engagement Feedback about the course	Not reported	The web-based psychoeducation course for caregivers seems to be especially suitable for those who have little experience as a caregiver. Less than two-thirds (18/30, 60%) completed the course. Feedback on the course varied; over half (10/17, 59%) of the caregivers considered the content to be very good or good, about half (9/17, 53%) considered the website layout to be good, only 6% (1/17) felt that the usability of the website was poor, and no one felt that it was very poor.
Ferré-Grau et	RCT	TIVA App	- Positive Mental Health Questionnaire (PMHQ)	Caregivers' outcomes:	Not reported	Caregiver outcomes:

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al., 2021			- Zarit Caregiver Burden Interview (ZBI-7).	- Positive mental Health; - Caregiver burden.		- Positive mental health: Personal factor (factor 1 of the PMHQ): showed a significant difference between the groups, but it was not clinically relevant (0.96; p=0.03). IG obtained a higher mean change for the overall PMHQ score (mean change between groups:1.40; p=0.24); after the third month of the intervention showed an increment of PMHQ scores. The mean difference of change in the PMHQ score showed a significant difference between the groups (11.43; p< 001; d=0.82); were reported significant changes in 5 factors: (F 5) Problem solving and self-actualization (5.69, p<0.001; d=0.71), (F2) Prosocial attitude (2.47; p<0.001; d=1.18), and (F3)Self-control (0.76; P= 03; d=0.50). Caregiver burden: results showed a decrease in caregiver burden in the intervention group.
Heckel et al., 2018	RCT	PROTECT	- Zarit Burden Interview; - Centre of Epidemiologic Studies – Depression scale (CES-D); - Supportive Care Needs Survey for Partners & Caregivers (SCNS-P&C); - Supportive Care Needs Survey (SCNS-SF34); - Health Literacy Questionnaire (HLQ); - Health education impact Questionnaire (heiQ); - Self-esteem subscale of the Caregiver Reaction Assessment (CRA); Self-designed utility assessment.	Caregivers' outcomes: - caregiver burden; - unmet needs; - self-empowerment and health literacy; - self-esteem; - depressive symptoms; - caregiver risk for depression. Patients' outcomes: - depressive symptoms, - unmet needs; health literacy.	HLS Health literacy: S1 – feeling understood and supported by healthcare providers; S2 – having sufficient information to manage my health; S3 – actively managing my health; S4 – social support for health; S5 – appraisal of health information; S6 – ability to actively engage with health care providers; S7 – navigating the health care system; S8 – ability to find good health information; S9 – understanding health information well enough to know what to do.	Caregiver outcomes: - Caregiver burden: no effect was observed after intervention p= 0.921; Caregiver unmet: reduction after intervention in both groups (IG baseline, mean = 2.66, 95% , CI [1.91–3.54]; group 1 month post intervention, mean = 0.85, 95%CI [0.42–1.44]; control group baseline, mean = 1.30 95%CI [0.80–1.94]; control group 1 month post intervention, mean = 1.02 95%CI [0.52–1.69]; p = 0.023); - caregiver self-esteem: decline in both groups from baseline to months 1 and 6 (p= 0.045). No significant difference between the groups over the time (p= 0.320); - Caregivers risk for depression: caregivers at risk had a significant effect on having sufficient information to manage their health (p = 0.040); patients' depressive symptoms, unmet needs; self-empowerment and health literacy levels no significant effects were found. Patient outcomes: - No significant differences between groups on patients' depressive symptoms, unmet needs and health literacy
Ferré-Grau et al., 2013	RCT	ATDOM (home care program) + PST (problem-solving technique)	- Questionnaire 'Ad-Hoc' (socio-demographic characteristics and care); - Goldberg Scale – anxiety and depression in family caregivers.	Caregivers' outcomes: - Depression and anxiety.	Not reported	Caregiver outcomes: Statistically significant improvement in symptom of anxiety (p<0.05) and depression (p<0.01) after intervention.

Legend: IG – intervention group; IC – control group; IC - confidence interval; F- factor.

Supplementary file1. Search strategy used for Medline®

Search	Query	Results
S1	"Chronic disease" OR "chronic illness" OR "complex health care needs" OR "special health care needs" OR diabetes OR diabet* OR "diabetes mellitus"	434,768
S2	family OR famil* OR peers OR friend* OR caregivers OR "fellow patient*" OR colleague* OR "internet contact*" OR "pen friend*"	821,108
S3	"Family relation*" OR "social support" OR "family function" OR "family dynamic*" OR "family coping" OR "family adaptation" OR "social support" OR "family dynamic*"	37,973
S4	"outcomes measure*" OR "intervention*" OR "Program*" OR "Promotion*" OR "Impact*" OR "project" OR "effectiveness" OR "Program Development" OR "Program Evaluation" OR "psychoeducational program" OR "evidence basic practice"	2,313,947
S5	S1 AND S2 AND S3 AND S4	902
	Limiters: English; Portuguese; Spanish; French, from 2013 to 2024	
Total		483

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Supplementary file 2. Summary information of each systematic review

Studies characteristics	Torenholt et al., 2014	Baig et al., 2015
Country	Denmark	USA
Databases used in search strategy and language limits	Scopus (including MEDLINE), CINAHL, PsycINFO, and ERIC Published in English	PubMed, CINAHL, and PsycINFO Published in English and Spanish
Range of included studies	All articles published up to October 2012	1994 to 2014
Number of studies included	10	26
Studies design	5 x RCT 2 x Non-randomized trial 2x Cohort 1x Pilot study	13 x RCT study design 11 x Prepost design 1 x Three arms study 1x Post-intervention measures
Original study exclusion criteria	People with diabetes under the age of 18 years and studies addressing illnesses or chronic conditions other than diabetes	Patients under the age of 19 or women with gestational diabetes. Studies focused only on diabetes prevention. Studies were excluded that only reported outcomes aggregated across patients and family members that, made it difficult to interpret the impact of the program on index patients with diabetes
Number of participants	Ranged from 10 to 160	Not clear
Intervention settings	4x interventions addressed specific cultural groups (Chileans, Native Americans, Native Hawaiians, and Mexican Americans) 6x without reference to a specific cultural group	22 x reported racial/ ethnic minority groups populations (American Indian, African American, Latino, and Asian, including Bangladeshi American and Korean American). 2x did not collect or report race/ethnicity data 2 x reported Native American communities Diverse settings: community health centers, other community sites, academic medical centers, churches, and veterans' administration hospitals
Intervention characteristics	3 x group sessions 4 x combined group sessions and individual sessions (people with diabetes and family members) 3 x individual sessions (people with diabetes and family members). Of the ten: - 8 x focused directed at the person with diabetes - 2 x focused equally on people with diabetes and family members	21 x group-based or one-to-one individualized counseling 1 x cooking class 4 x home visits. Of this: - 4 x incorporated home visits - 3 x technology strategies
Intervention duration and number of sessions	Ranged from 3 to 12 months Included between 3 and 16 sessions	Not clear information
Intervention themes	10 x addressed knowledge of diabetes and lifestyle. Of this: - 6 x addressed non-family psychosocial issue - 6 x addressed family issues (acquisition of skills by family members' support in making dietary and exercise changes and learning methods for	Clinical (Dietary behaviors, healthy meals, physical activities, HbA1c) Psychosocial (manage stress family members' engagement and traditional cultural values regarding familiar and social relationships, family members' supportive behaviors)

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	avoiding or counteracting stimuli that elicit negative behaviors)	
Intervention-specific theories or theoretical models	3x Social Learning Theory 1x Innovative Care for Chronic Conditions 1x Self-Regulatory Model of Illness Behavior 1x Social Action Theory 1x Interdependence Theory and Family Systems Theory 1x Family dynamics (focused on behavioral skills derived from social support)	7 x theoretical framework but unclear information was provided
Interventionists / professionals who performed the intervention	Not clear	Community health workers (CHWs), promotors, pharmacists, certified diabetes educators (CDEs), peer or lay leaders, dietitians (RDs) or nutritionists, mental health providers, nurse practitioners, health educators, tribal elders/leaders, and dentists
Control	10 x control group	Control group (usual care or individual educational sessions)
People with diabetes outcomes of interest	10 x individual outcomes described in four categories (biological; behavioral/ knowledge; psychosocial)	Included - 13 x diabetes knowledge - 15 x health habits - 1 x emergency room and hospitalization rates - 2 x costs of intervention - 3 x depression and stress related to diabetes
Family outcomes of interest	2 x reported biological outcomes (blood sugar levels, calorie, and exercise) 3 x reported family-specific measures (involvement, support, and functioning)	17 x do not report 1 x physical activity and support 2 x family rates engagement in interventions 1 x family biological outcomes (waist circumference, blood pressure, physical activity, fruit and vegetable consumption, BMI, and diabetes knowledge) 6 x reported data related to the involvement of family members (support, diet)
Methods of analysis	Narrative synthesis	Narrative synthesis
Definition of family	4x Intimate relationship in same household 4 x Same household but not necessarily an intimate relationship 2x Broad, including friends and co-workers	12 x family are spouses, parents, children, or relatives: - 3 x preferably a spouse - 1 x living in diagnosed person's household 9 x family members/ close friends/ supportive person: - 1 x friend had to be living in diagnosed person's household - 1 x study reported that a family member or close friend must be someone living outside the patient´s house
Family involvement (including strategies)	4 x interventions emphasized active participation in physical activity, cooking, active problem-solving, goal setting, and building self-efficacy 4 x interventions did not emphasize active participation	20 x invited family to attend the intervention classes or meetings 4 x reported that family involvement 5 x family member was encouraged to participate 11 x included family-themed topics in the education sessions 7 x reported family participation in physical activities or shared a healthy meal

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		Family members received notifications of the results and suggestions for self-management support through prerecorded support messages. Motivational coaching to family members to provide effective feedback to the patient and help assess barriers to self-monitoring of blood glucose. Other studies reported patients' and partners participation in exercises to promote collaborative problem-solving
Bias appraisal (including instruments used)	Not clear. Most original studies reported an unclear risk of bias	Adapted questionnaire based on the Downs and Black guidelines. Studies rates ranged from 10 to 24,5, mean score of 18
Follow-up	3 and 6 months	Immediate post-intervention, 12 months, 24 months, and 36 months
Findings/conclusions	Family-based interventions had positive impact in improving biological outcomes levels, diabetes knowledge, attitudes about diabetes, and increased perceived family support.	Intervention participation was associated with outcomes improvement: physical activity, family support, family rates engagement in interventions, and clinical outcomes (waist circumference, blood pressure, physical activity, fruit and vegetable consumption BMI, and diabetes knowledge) Patients and family members reported qualitative outcomes improvement, including family members' ability to support (emotional and instrumental). Family members described feeling more confident in supporting their loved one with diet and also family members' improvement of their own diet. Were also reported positive effects of family involvement.

(Continued)	**Pagmunkas et al.,2017**	**Thirsk & Schick-Makaroff, 2021**
Country	Thailand	Canada
Databases used in search strategy and language limits	PubMed, CINAHL, and Scopus Published in English	MedLine, CINAHL, PsycINFO, and PubMed Published in English
Range of included studies	2008 to 2016	2008-2019
Number of studies included	24	6
Studies design	19 RCT 3 quasi-experimental design 2 mixed- methods design	3 x qualitative design 1 x mix-methods 1 x exploratory design 1 x not clear
Original study exclusion criteria	Studies focused on medication alone Intervention that did not include a family component Studies with a single design, with descriptive design, qualitative research, no control group, not published in an academic journal (e.g., unpublished dissertation) Studies focused on diabetes prevention or targeting gestational diabetes population	Studies published as abstracts, in the gray literature, and/or in other languages. Studies focused on type 1 diabetes, gestational diabetes, child/adolescent diabetes groups, and peer or social network focus. Qualitative research, without interventions. Studies focused only on individual patients included in intervention.
Number of participants	Not clear	177 patients, 31 family members or friends, and 20 clinicians or community health workers
Intervention settings	23 x were conducted in Western countries	6 x conducted in the United States

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	1 x Asia country	Included specific cultural groups defined by race, ethnicity, socioeconomic status, and geography (rural African American families, Latino immigrant families, Mexican-American families in southern Arizona, and American Indian/Alaskan Native)
Intervention characteristics	9 x individual format 10 x combination of individuals and group format. 16 x combined didactic and participatory learning with strategies (goal setting, action planning, problem-solving and follow-up strategies) 2 x used technology to deliver health information (DVD-based training program, 1 Bluetooth) 1 x cooking class to demonstrate healthful foods 1 x offered diabetes telemonitoring calls using the mHealth + Care Partner 7 x used diabetes handouts/booklets (diet, exercise, medication, eye and foot self-care) 2x reported the use of educational materials (Colorful, Handouts, Brochure, Cookbook, exercise videotape, pedometer, foot care kit, pictures illustration, handbook, games, food models, cardiovascular training equipment, brochure)	1 x reported the development of behavioral intervention using motivational interviewing and behavioral activation 1 x included three home visits and five educational sessions, 2 x participation in celebratory events, including diabetes and family curriculum. The use of focus group and interviews were also reported. 1x focus groups/interviews
Intervention (duration and frequency)	Duration ranged from 2 hours to 6 months Frequency ranged from 1 to 8 eight	1x 12-week program (3 home visits, 5 educational sessions and 2 celebratory events)
Intervention themes	Clinical (Blood glucose levels (HbA1c levels, dietary, exercise behavior aspects, medication adherence, diabetes management behaviors) Psychosocial (perceived support, self-efficacy, diabetes knowledge, quality of life, communication and supporting skills, effective day-to-day coping)	Diabetes management for the patient (managing diet, exercise, and medication) Supportive and obstructive family interactions Family member's knowledge about diabetes management
Intervention-specific theories or theoretical models	1x Social Cognitive Theory	Not clear
Interventionists (professionals that performed the intervention	Not clear	1x community health workers
Control	Not clear	Not reported
People with diabetes outcomes of interest	23 x clinical outcomes. Including: - 10 x HbA1c - 5 x dietary modification support and blood pressure level improvement - 2 x body mass index - 3 x lipid profile 23 x self-management behavior (diet, physical activity, blood glucose monitoring, foot inspections, and medication adherence) 23 x psychological	6 x diabetes management: - 1x focused on self-management and glycemic control - 1x focused diabetes care and empowerment for healthy lifestyle - 1 x treatment adherence, glycemic control, and health-related quality of life - 1 x self-management behaviors and depression

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		- 1 x diabetes self-care by addressing supportive and obstructive family interaction
Family outcomes of interest	1 x family support and positive communication	1 x reported family attendance 2x diabetes knowledge (healthy food, choices, hereditability of diabetes, importance of exercise), and how to be supportive 1 x supportive and obstructive family interaction 1x reported pre-posttest measures of family system and behavior change
Methods of analysis	Narrative synthesis	Qualitative meta-synthesis
Definition of family	Not clear	1x described family according to blood ties and extended family beyond blood relatives
Family involvement (including strategies)	13 x involved patients and family members were involved as a unit intervention and required family members to attend the education classes or meetings 8 x asked family members to provide support in relieving stress, denial, and maximizing environmental conditions 1 x family members were needed to assist and support patients in self-management practices by helping patient with strategic planning, goal setting, and problem-solving 1 x use of a speakerphone to improve communication skills among couples and family members and to support and solve problems of behavior change and goal setting. 1 x family members were instructed to provide guidance and support for self-management and help assess barriers to effective self-management behavior 1 x family member received email updates	1x family member was invited to 1 session 1 x reported family member involvement as optional 4 x no clear information was provided
Bias appraisal (including instruments used)	Not clear	6 x Critical Appraisal Skills Program, qualitative checklist
Follow-up (including strategies and time)	Time not reported Strategies: - 12 x face-to-face - 9 x telephone - 7 x mixed face-to-face follow-up and telephone or computer-based - 1x mailing	Not reported
Findings/conclusions	Results confirmed that family involvement positively impacts health outcomes in persons with diabetes.	Family involvement in diabetes intervention is positively associated with improving outcomes in people with diabetes. Authors emphasized the limited qualitative research available to help understand family-based interventions.

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Studies characteristics	Zhang et al., 2022
Country	China
Databases used in search strategy and language limits	PubMed, Embase, PsycINFO, CINAHL, the Cochrane Library Central Register of Controlled Trials, and Web of Science Published in English
Range of included studies	From the beginning of the database through 5 March 2021
Number of included studies	23
Studies design	23 x RCT
Original study exclusion criteria	Quasi-experimental trials, abstracts, protocols, conference papers, and academic dissertations were excluded
Number of participants	3114 total participants (including 1555 in experimental group and 1559 in control groups)
Intervention settings	8 x reported culturally tailored family intervention
Intervention characteristics	16 x group sessions based on the family 2 x group sessions based on couples Strategies included face-to-face sessions, home visits, telephone calls, messages or video
Intervention duration and frequency	Ranged from 1 to 12 months Frequency not clear
Intervention themes	Diabetes specific knowledge Family emotional support Self-efficacy Psychosocial (depression, stress)
Intervention-specific theories or theoretical models	Studies mainly based on the social cognitive, self-efficacy, empowerment, or health belief model.
Interventionists (professionals that performed the intervention	Nurses, physicians, clinical health workers, pharmacists, dietitians, psychologists, researchers, medical teams, or others
Control	23 x control group. Includes: - 11x usual medical care - 3x diabetes self-management education - 5 x individual-based intervention - 3 x wait-listed controls - 1 x did not receive any instruction
People with diabetes outcomes of interest	23 x patients HbA1c levels (mmol/l or %); From baseline to post-intervention were reported: - BMI - Body weight - Diastolic blood pressure - Blood lipids - 7 x diabetes self-management behavior - 7 x diabetes knowledge - 2 x adherence to diabetes medication - 8 x diabetes self-efficacy - 3 x diabetes-stress

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	- 2 x depression in patients with diabetes
Family outcomes of interest	3 x involvement of family (included the positive and negative dimensions) 3 x family support 1 x family efficacy
Methods of analysis	Meta-analysis
Definition of family	6 x family members are those living together with adults with diabetes or who had ongoing contact with the index participants, such as caregivers, blood relatives, or spouse
Family involvement (including strategies)	Not reported
Bias appraisal (including instruments used)	Cochrane Collaboration Risk of Bias Assessment Tool
Follow-up	Follow-up (≤6 months or >6 months)
Findings/conclusions	Family-based intervention was associated with positive improvement on diabetes control, diabetes self-care, psychological well-being, and family support of adults with diabetes.

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Supplementary fille 3. CERQual quality evidence summary

Authors, year of publication	Methodological limitations	Coherence	Adequacy	Relevance	CerQHigh confidence
Thirsk & Schick-Makaroff, 2021	Minor concerns regarding methodological limitations	Minor concerns about coherence	Minor concerns about adequacy	Minor concerns about relevance	High confidence level

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Supplementary fille 4. GrADE quality evidence summary

Authors/ Year	Risk of bias	Inconsistency	Imprecision	Indirectness	Publication bias	Overall evidence assessment
Zhang et al., 2022	Low risk of bias Calculated Egger regression test (p = .97)	Low risk of inconsistency	Moderate risk of imprecision (heterogeneity F= 61,1%)	Low risk of indirectness	Low risk of publication bias	High quality evidence
Pagmunkas et al., 2017	Moderate risk of bias (variability and missing information on studies methodologies. Included two mixed-methods design)	High risk of inconsistency (heterogeneous methodology made it difficult to compare the size effect)	High risk of imprecision (sample size not clear)	High risk of indirectness (effect size of each study outcome was not described)	Moderate publication bias (positive findings tend to be published more)	Low quality evidence
Baig et al., 2015	Moderate risk of bias (mean quality score = 18, the lowest score in studies' quality assessment were in attempt to blind the study subjects, and attempt to blind those measuring the main outcomes, reporting of adverse events)	Moderate risk of inconsistency (heterogeneous in the designs and varying patient populations and settings, we could not compare effect sizes across studies)	High risk of imprecision (sample size not clear. the lowest score in studies' quality assessment were in the use of a representative sample and in the report of sample-size calculation)	Moderate risk of indirectness (assessment of patient outcomes with family involvement were not similar in all interventions)	Moderate risk of publication bias (positive findings tend to be published more)	Low quality evidence
Torenholt et al., 2014	Low risk of bias	High risk of inconsistency (heterogenous methodology and lack of information made it difficult to compare the size effect)	High risk of imprecision (study sample ranged from 10 to 83)	High risk of indirectness (inconsistency of the information reported in original studies)	High risk of publication bias (study sample ranged from 10 to 83)	Low quality evidence

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CAPÍTULO IV. DETERMINAR NECESSIDADES

O envolvimento da família na gestão da diabetes é reconhecido como essencial para melhorar os resultados em saúde e a qualidade de vida das pessoas diagnosticadas. As necessidades do adulto com diabetes têm sido amplamente descritas na literatura, evidenciando desafios relacionados com a autogestão, a adesão ao regime terapêutico e a sua saúde mental (Alexandre et al., 2021). No entanto, persistem lacunas no conhecimento sobre as necessidades específicas dos familiares que desempenham o papel de suporte à pessoa diagnosticada, o que pode limitar a eficácia das intervenções existentes. Compreender essas necessidades, juntamente com as do adulto diagnosticado, é crucial para o desenvolvimento de estratégias mais personalizadas e efetivas, que promovam tanto a autogestão da doença como a dinâmica de apoio familiar.

Este capítulo centra-se na identificação e análise dessas necessidades, baseando-se em evidências obtidas através de uma metodologia em duas fases. A primeira incluiu uma *scoping review*, que mapeou as lacunas na literatura e evidenciou os desafios enfrentados pelas famílias no contexto da diabetes. A segunda fase inclui os resultados de um grupo focal com adultos diagnosticados e seus familiares, permitindo uma análise aprofundada das dinâmicas familiares e dos fatores que influenciam a gestão da doença.

Além da revisão da literatura, a experiência clínica da equipa de investigação e reuniões informais com profissionais de saúde reforçaram a relevância da família como unidade de cuidados. Estas interações destacaram a ausência de uma abordagem sistemática à avaliação familiar nas práticas clínicas, sublinhando a importância de utilizar instrumentos validados e adaptados culturalmente para orientar intervenções e avaliar o impacto das dinâmicas familiares nos resultados em saúde.

Os resultados apresentados neste capítulo oferecem uma base sólida para o desenvolvimento de intervenções centradas na família, como o programa *Juntos com a Família + Capazes*, e enfatizam a necessidade de integrar práticas que promovam o envolvimento familiar como elemento essencial na gestão da diabetes e de outras doenças crónicas.

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Integrating literature and family insights: exploring the needs of families supporting adults with diabetes

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Introduction: The considerable influence that family members can have on diabetes management is well recognized. Therefore, it is crucial for professionals to acknowledge the impact of the diagnosis on family members. This study aimed to comprehensively identify and understand the needs of family members with an adult diagnosed with diabetes using a two-phased research design.

Methods: Phase 1 was a scoping literature review using databases such as MEDLINE®, CINAHL®, SciELO, and PsycINFO, and gray literature from the Scientific Open Access Repository of Portugal and OpenGrey, focusing on studies from 2017 to 2023, adhering to the Joanna Briggs Institute and PRISMA guidelines. Phase 2 involved a focus group to gather qualitative data on family experiences, which was analyzed using content analysis and following the Consolidated Criteria for Reporting Qualitative Research.

Results from both phases revealed five themes: Communication and emotional expression within families, the impact of diabetes on the family, diabetes-specific knowledge, socio-cultural and environmental influences on diabetes management, and communication with healthcare providers. Integrating these findings highlighted the specific needs of families, suggesting that tailored interventions should be developed to enhance diabetes management support and promote overall family well-being.

KEYWORDS

nursing, family, social support, diabetes mellitus, health impact assessment, nonpharmacological interventions

1 Introduction

Diabetes mellitus (DM) affects 537 million people worldwide, and projections show that around 783 million adults (20–79 years) will be living with this disease (1). Present on global political agendas, DM has a profound impact at various levels, including personal, familial, social, and healthcare systems, due to the severity of its complications and the resources required for its control (1).

Diabetes management and related health outcomes are influenced by various factors, including ethnicity, cultural background, socioeconomic conditions, and access to healthcare. These differences can significantly impact the management of diabetes and related health outcomes.

The growing prevalence of diabetes accentuates the urgent need to develop more effective interventions that go beyond traditional approaches. Therefore, family involvement in diabetes management and interventions has been emphasized in the literature as a determining factor for success, with a positive impact on patient outcomes (2, 3).

However, to promote support for adults with diabetes, effective strategies that holistically address all the factors impacting family members' health are essential.

The diagnosis of diabetes affects not only individuals but entire families, restructuring daily routines and impacting their emotional and financial well-being (4).

Managing diabetes imposes lifestyle changes such as adhering to a strict diet, regularly monitoring blood glicose levels, and consistently taking medication or insulin therapy (5). These adjustments can be demanding, requiring a collective effort from family members to support the diagnosed person.

Extensive research has been conducted on family involvement in diabetes management and its positive impact on patient outcomes (6, 7). The literature highlights the significant role of family involvement, associating it with improvements in patient outcomes and the maintenance of self-management behaviors (2, 3, 8).

Several family-focused interventions have been developed and assessed in recent years, with their effectiveness demonstrated (9). Most of these interventions aimed to improve family-specific diabetes knowledge and enhance their skills to provide instrumental support to individuals with diabetes (10). However, despite the increase in diabetes-specific knowledge among family members, patients still identify their relationships with family members as critical and often feel that family members can be barriers to changing lifestyle habits (11). These behaviors, described in the literature as non-supportive or sabotaging, may result from researchers and health professionals neglecting the importance of family conflicts, the diversity of relationships among members, and family cultural beliefs (12, 13).

The significant potential that family members have to influence diabetes management is well recognized. Therefore, professionals need to recognize the impact of the diagnosis on family members, particularly those involved in supporting self-management activities or directly performing related tasks and responsibilities (10, 14). Health professionals should recognize and address family emotional needs, how they interact and behave, how they communicate and solve problems, the influence of their health patterns on healthy choices, the cultural impact and beliefs in disease management, and the social-economic and environmental impact of their contexts (14).

Through this comprehensive analysis, professionals and researchers will be able to develop family-tailored interventions that improve diabetes management outcomes and supportive family interaction patterns (10, 15).

This study aims to comprehensively identify and understand the needs of family members and answer the following research questions: What are the specific needs and challenges families face in managing diabetes within their daily routines? How do family members perceive their roles and responsibilities in the care and management of a family member diagnosed with diabetes?

2 Methods

A two-phased research design was employed. In phase 1, a scoping review was performed. In phase 2, a one-round focus group survey was conducted with adults with diabetes and family members who support them in disease management.

2.1 Phase 1: scoping review

This scoping review was performed according to the Joanna Briggs Institute (JBI) methodology for scoping reviews (16, 17). This Phase 1 aimed to explore and comprehensively identify and understand the needs and perceptions of family members of adults with diabetes described in the literature.

2.1.1 Search strategy

A three-step search was performed by two independent reviewers. An initial search was limited to PubMed and CINAHL, using the search terms "adult with diabetes" OR "diabetic" AND "family needs" OR "family assessment" OR "needs assessment." This search aimed to identify the indexed and free-text terms most frequently used in articles developed on this topic by analyzing their titles, abstracts, and keywords of the studies. A second search was conducted using indexed search terms and keywords, adapted and individualized to each electronic database, including MEDLINE ®, CINAHL®, SciELO - Scientific Electronic Library Online, and PsycINFO (access via EBSCOhost Web). A third search was developed using gray literature. The gray literature and unpublished studies were mapped using the databases: RCAAP (Scientific Open Access Repository of Portugal), and OpenGrey. The search strategy used for MEDLINE® is provided in Supplementary material 1.

2.1.2 Inclusion criteria

The scoping review search was limited to studies published between 2017 and 2023 to ensure the inclusion of the most recent guidelines and advancements in diabetes care. The inclusion criteria for the scoping review were defined using the PCC (Population, Concept, and Context) mnemonic.

- Population (P): studies conducted with participants that included family members of adults diagnosed with diabetes mellitus, both being 18 years of age or older.
- Concept (C): studies focused on identifying and understanding the specific needs, perceptions, and challenges of family members involved in diabetes management;
- Context (C): studies conducted in any healthcare and community settings, including hospitals, clinics, home care, and community health programs, where family needs in diabetes support are relevant.
- Types of evidence: various studies were included to understand the needs of family members supporting adults with diabetes. Qualitative studies to capture insights and personal experiences and quantitative studies. Mixed-methods studies that integrated

both qualitative and quantitative data for a comprehensive understanding. Review articles, including systematic reviews and meta-analyses, synthesized existing research on family involvement in diabetes care.

Studies published in English, Portuguese, Spanish, and French were included based on the reviewers' level of linguistic proficiency, ensuring greater rigor in the selection of evidence and data extraction.

2.1.3 Data collection

This process was performed by two reviewers. Articles were screened for inclusion using Endnote X9® Software reference management software (Clarivate Analytics, PA, USA), and the duplicate references were identified and removed. Two reviewers independently screened the titles and abstracts. The potentially relevant full-text information was assessed by the same two authors. Disagreements between the two reviewers at any stage of this process were resolved by consensus or through analysis and discussion by a third reviewer. The selection process was guided and presented using the PRISMA Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews -PRISMA-ScR (18).

2.1.4 Data extraction

Two independent reviewers developed the data extraction process for this scoping review. A data extraction tool was developed and tested to ensure comprehensive and accurate collection of relevant information from the selected studies. To ensure accuracy, two independent reviewers conducted data extraction, with discrepancies resolved through discussion or consultation with a third reviewer.

The extracted data included the following information: author(s), year of publication, title, study design and population, and settings. Additional relevant details encompassed outcomes, needs, and perceptions of family members related to family involvement in diabetes management. The synthesis of study information was compiled into a table and presented through a narrative synthesis.

2.2 Phase 2: focus group

A qualitative descriptive approach was conducted using focus groups to explore and describe the lived experiences of family members of adults diagnosed with diabetes. We intended to understand how family members perceived the disease and its management without relying on preconceived theories or frameworks (19, 20). The Consolidated Criteria for Reporting Quality Research (COREQ) guidelines were used according to the Enhancing the Quality and Transparency of Health Research (EQUATOR) network (21).

2.2.1 Participants and recruitment

Participants were selected based on specific criteria to ensure relevance to the aim of the study. These included adults diagnosed with diabetes and their family members aged 18 years or older who are involved in diabetes support. Although it is well-recognized that the majority of individuals diagnosed with diabetes are living with type 2 diabetes, no distinction regarding the type of diabetes was made during the recruitment process for the focus group (1). This decision was made to ensure inclusivity and to reflect the diverse experiences and challenges faced by families of individuals with diabetes. The concept of family used for participant selection was "family is who its members say they are" [(22), p.55]. Individuals with cognitive impairments were excluded.

Healthcare professionals at the Family Health Unit made an initial contact by phone to inquire about individuals' availability to participate in the study. The researcher conducted an initial screening to ensure participants met the inclusion criteria. Efforts were made to ensure a diverse group of participants in terms of age, gender, and socioeconomic status. Participants were grouped, and the focus group was scheduled at a convenient time for them, and reminders were made by phone to confirm attendance.

This focus group was initially conducted to gather participants' opinions about a proposed intervention being developed for adults with diabetes and their families. However, during this session, several important themes emerged. Given their relevance to understanding the family perspective, these themes will be used in this article to provide a comprehensive understanding of the participants' perspectives found in the scoping review.

2.2.2 Setting

The study was conducted at a family health unit in Portugal, where the individuals receive primary care services.

2.2.3 Data collection

The focus group took place in May 2024 and comprised adults with diabetes and their family members. After written informed consent, the voice recordings were used for data collection, with the consent of all participants. Voice recordings were intended solely to assist in transcribing the focus group content. The moderator role was assumed by the primary author, a PhD Nursing Science student currently holding a research grant. She has extensive background knowledge on the topic gained through her professional experience in clinical practice and research. This has been her area of investigation for the past 8 years. The moderator always took into account the assumptions inherent to the focus group and ensured a productive discussion by adhering to the principles of focus groups, refraining from giving personal opinions, and steering the conversation toward the study's objectives (23). Another nurse, also a PhD Nursing Science student with experience in qualitative research, assumed the role of observer and took notes during the session. Data saturation was achieved by identifying the repetition of information. The focus group session took an average of 2 h.

2.2.4 Ethical considerations

The ethics approval for this study was obtained from the Ethics Committee from Alto Minho Local Health (Decree-Law No 97/95 of 10 May, revised by Decree-law No 8072018 of 15 October). All participants who met the inclusion criteria were provided detailed information about the study, including its objectives, procedures, and benefits.

The confidentiality and anonymity of participants' identities and their responses were ensured by the researchers. Participants were also informed that their participation was voluntary and that they could withdraw from the study at any time without any consequences. All participants were asked to provide written informed consent before participating in the focus groups.

2.2.5 Data analysis

In this study, the content analysis was developed using Mayring's Qualitative Content Analysis (QCA) (24). This systematic approach allowed us to understand the textual data, prioritizing the creation of a coherent and easily understandable text while respecting grammatical structure and preserving the participant's original intent. This method provides a clear process that enhances the reliability and validity of the analysis.

We considered the following main phases: (i) formulating a specific research question about family members' involvement in diabetes management; (ii) pre-analyzing the transcript data and notes and selecting the material relevant to these questions; (iii) developing a coding frame with categories. Finally, a conceptual structure was obtained, composed of the main themes and categories of analysis (24).

2.2.6 Validity and reliability

To ensure the validity and reliability of the focus group data, we followed the guidelines provided by the COREQ (Consolidated Criteria for Reporting Qualitative Research) checklist (21). We ensured the transferability of the results by establishing clear criteria for participant selection and achieving diversity in terms of age, gender, and socioeconomic status. During the focus groups, a trained moderator facilitated the discussions while an observer took detailed notes, ensuring consistent data capture. All sessions were audio-recorded with participants' consent, and the recordings were transcribed verbatim.

To enhance credibility, we checked the preliminary findings with participants to confirm the accuracy of the interpretations. Inter-coder reliability was ensured by having two independent researchers code the transcripts and resolve discrepancies through discussion. These steps helped maintain the data's dependability and confirmability, providing a robust foundation for the study's conclusions. Excerpts from the participants' statements were included to demonstrate the meanings assigned by family members. Each family member is referred to by the letter "F," followed by a unique identification number, such as F1.

3 Results

3.1 Phase 1: scoping review results

The search strategy identified 1,163 publications. After excluding 72 duplicates, 1,091 publications were selected for title and abstract analysis. A total of 11 publications were selected for full-text analysis, with 8 studies included in the review. The study selection process is summarized in the PRISMA flow diagram (Figure 1).

All the studies included are written in English. Five of eight were developed in Europe (25–29), two in the United States of America (14, 30), and one in the United Kingdom (30). Regarding the study design, two qualitative studies were included. (26, 30), one described a secondary analysis (31), two were cross-sectional studies (27, 28), one integrative review (25), one was descriptive (14), and one was quantitative (29). The majority of the studies were developed in community settings. More detailed information about studies is described in Supplementary material 2.

Based on the guiding questions of this study, the analysis of the studies allowed the identification of needs and perceptions of family members of adults diagnosed with diabetes. The relevant information was gathered and organized into two main themes, each supported by several categories (Figure 2).

The first theme, "Diabetes Management in the Family," is supported by the following categories:

(i) Family members' communication patterns and challenges: disruptive family behaviors were reported, such as arguing about diabetes management, difficulties in communication, gender differences in communication patterns—with men being more authoritative in their speech—challenges in sharing knowledge within the family, inability to influence the diagnosed person, and conflicts with the diagnosed person due to diabetes activities and targets (25, 26, 30).

(ii) Impact of diabetes diagnoses and management activities on family: regarding the diabetes diagnosis and management, family members reported anxiety, stress, anger, distress, frustration, burden regarding diabetes management activities, increased sense of responsibility, lack of confidence, fear, and nervousness facing the diabetes challenges, and feelings of being undervalued in their role in diabetes management by patients (14, 26–31).

(iii) Family members' diabetes-specific knowledge needs: family members reported a lack of diabetes-specific knowledge, including information about medications, and expressed a desire to engage more frequently with health services to become more involved in diabetes care (14, 26, 30).

(iv) Communication between family and healthcare providers: in this category was reported the lack of time with healthcare providers, confusion about information provided by professionals, and inconsistent information provided in the appointments (14)

(v) Family adjustments for diabetes care: one study reported family members' preference to remain uninvolved in diabetes management (25). However, the remaining results showed that most family members expressed significant responsibility for diabetes management activities, its challenges, and targets (14, 26–31).

(vi) Impact of diabetes on family members over time: the diabetes diagnosis and family members' increased responsibility for diabetes management and patient needs often leads to a decline in family members' health over time (27, 31). The presence of diabetes complications is highlighted as one of the factors that notably decreases family members' quality of life (29). The same authors reported several difficulties family members face in maintaining their social connections and support networks, as well as the impact of the disease on the family's financial conditions.

(vii) Family members' needs for healthcare services and education: as mentioned above, the lack of knowledge is evident among the relatives of adults with diabetes. Consequently, they also described the need for more regular check-ups to prevent complications and education interventions to improve patient knowledge about complications (29, 30). The same authors described the family members' need for peer support and psychologist intervention in the disease management process.

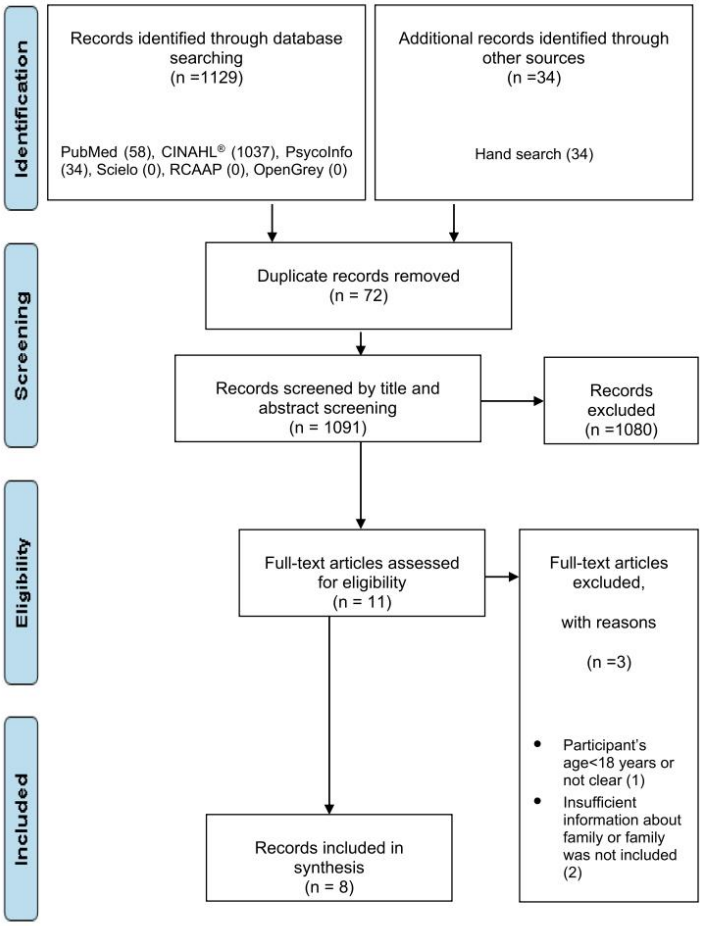

FIGURE 1
PRISMA flow diagram of study selection.

The second main theme, "Impact and Influence of Socio-Cultural and Environmental Contexts on Diabetes," is supported by one category:

(viii) Barriers to adhering to a healthy lifestyle: in this category, family members expressed difficulties in buying healthy and affordable food, societal discrimination against the disease, lack of safe places for physical activity, and inadequate work conditions for managing the diabetes activities by patients (28)

3.2 Phase 2: focus group results

The sample comprised 10 participants: five adults diagnosed with diabetes and five family members. All individuals contacted to participate in the study accepted and none dropped out. The reasons for this high participation rate include a strong interest in the topic and the personal relevance of the subject matter to the participants. The adults with diabetes were predominantly male, ranging in age from 58 to 83 years, with a mean age of 71.6 years. Of the five adults diagnosed with diabetes, only one had type 1 diabetes, while the remaining four had type 2 diabetes. Among the participants with type 2 diabetes, all reported using oral antidiabetic medications, with one participant also undergoing combined therapy that included injectable insulin. The duration of diagnosis ranged from 2 to 18 years, with an average of 7.8 years. The family members were predominantly female, aged between 54 and 78 years, with a mean age of 67.4 years. They provided support in diabetes management for an average of 7.8 years, ranging from 2 to 18 years. All participants lived with the person diagnosed with diabetes. The COREQ Checklist details are provided in Supplementary material 3.

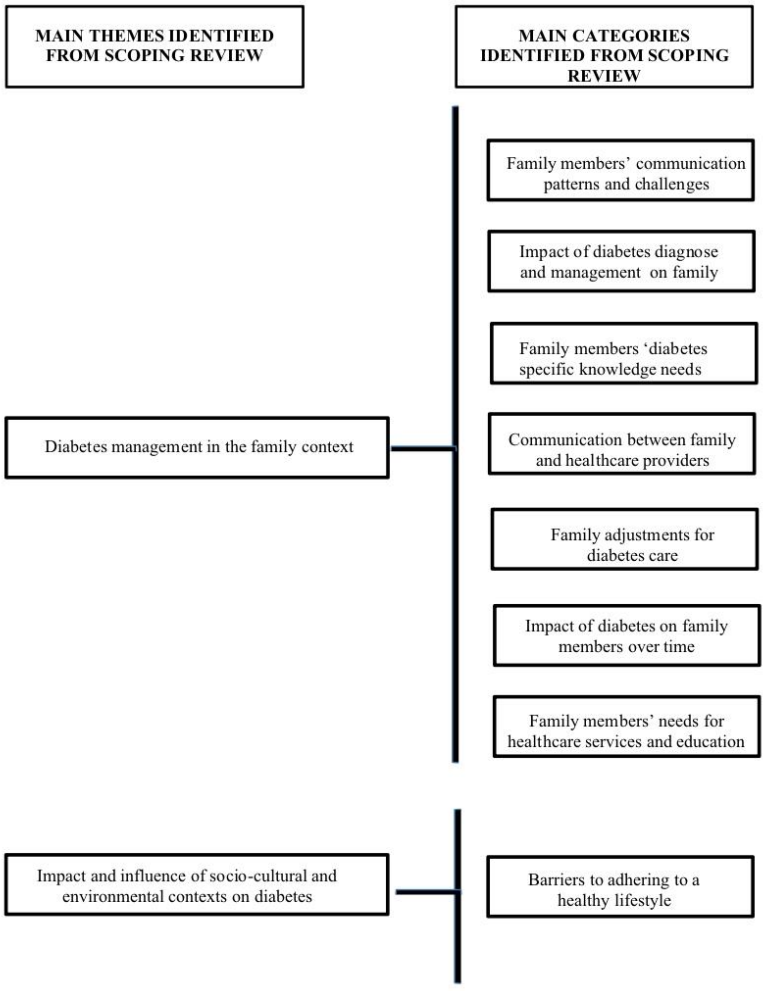

FIGURE 2
Scoping review overview of the themes and categories.

Three themes emerged from data analysis: challenges in diabetes management activities, socio-cultural and environmental contexts influence on diabetes management, and communication challenges. The theme "challenges in diabetes management activities" is supported by two categories: the influence of family and its cultural patterns on adhering to healthy habits and the family's diabetes-specific knowledge and education needs. The theme "socio-cultural and environmental contexts influence on diabetes management" is supported by three categories: availability of healthy food choices; challenges in grocery shopping activities, and physical activity infrastructures. The third theme, "Communication challenges," is supported by two categories: barriers to communication between family and healthcare providers and barriers to family members' communication (Figure 3).

3.2.1 Theme 1: challenges in diabetes management activities

3.2.1.1 Category: influence of family and its cultural patterns on adhering to healthy habits

The participants expressed difficulty adhering to healthy diets. The influence of family and cultural dietary habits on their food choices was evident, and they missed the old foods they ate before their family member was diagnosed with diabetes. They feel they have to eat

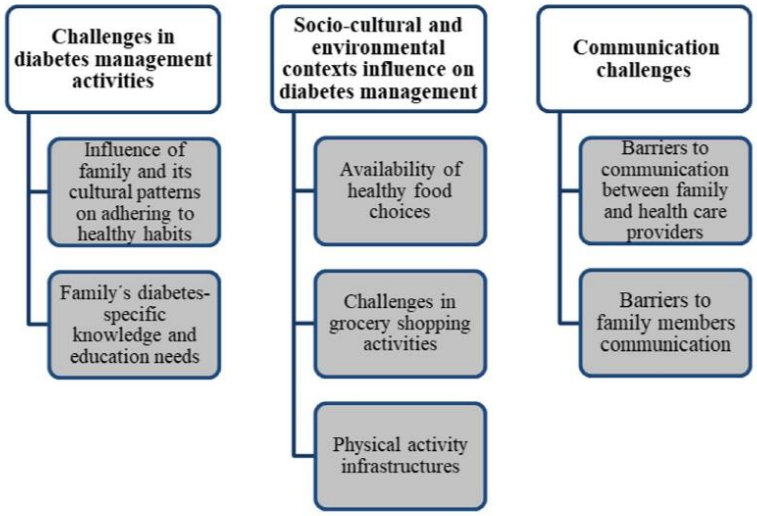

FIGURE 3
Focus group overview of the themes and categories.

healthy foods to help their relative who was diagnosed with diabetes, although they need to eat what they want on festive days, independent of patient choices.

> "… do you know what it means to eat good food? In this region, we have the best comfort food, but now I cannot eat that... our traditional foods are the best. During Christmas and weddings, I eat a lot of everything and do not care about dietary habits." F1.
> "… good food was in the past, now… we enjoyed eating vegetable soup with beans and bread inside" F2.
> "…at home, we do not eat anything like we used to (eat unhealthy food)… now we eat what the doctor recommends, except at Christmas and on birthdays." F2.
> "… it has to be (food choices)... we need to change our diet because we do not want diabetes complications" F1.

Regarding family habits related to regular physical exercise, family members reported difficulty in maintaining regular physical activity habits. Regular physical exercise is not a priority for them, even if their relative with diabetes needs or wants their company or encouragement. They expressed difficulty finding time to exercise due to their busy schedules. Although most are retired, they feel that their daily activities consume much of their time, leaving few opportunities to exercise with the patient. Additionally, they believe that activities such as taking care of their vegetable gardens are sufficient for maintaining their health, ignoring the patient's needs.

> "…more time? I do not have any extra time to spend to walk... I'm retired, but I have a lot to do in my daily life." F1.
> "…I cannot… I have to take care of our vegetable garden, that is a good exercise (…), and I am responsible for picking up my grandchild from school every day at 3:30 PM." F3.

3.2.1.2 Category: family's diabetes-specific knowledge and education needs

Family members expressed the need for more information about diabetes management to better support the diagnosed individual, particularly in helping them choose healthy foods. They suggested that interventions would be an effective way to increase their knowledge, specifically group interventions consisting of peers, including the diagnosed individual and their family, as well as professionals. Family members described the need to share knowledge and experiences with peers who also support an adult diagnosed with diabetes.

> "…these meetings with people who talk about the same problems we face are important because we get tips and experiences from others regarding diabetes issues." F1.
> "…we need more moments like this to learn about food and medication. We need more tips and advice…" F2.
> "… I agree…" F3.
> "… I make an effort to read food labels to help my wife choose healthy options… but the list of ingredients is huge... I do not know what those ingredients with strange names are… and which choose…" F2.

3.2.2 Theme 2: socio-cultural and environmental contexts influence on diabetes management

3.2.2.1 Category: availability of healthy food choices

Family members expressed frustration with the limited availability of healthy products in their area of residence. They reported that several local producers have closed their shops, and nowadays, they can only buy more nutritious foods, such as vegetables and fruit, from neighbors (who grow vegetables and other produce), or they have to

grow them themselves. They feel that the products available for sale are unhealthy and overly processed.

> "…here, the good shops have closed. The bakery with artisanal bread has closed too... now the bread is poorly made and not healthy." F3.
> "...nowadays, everyone has to buy vegetables at the supermarket. I do not like that; it's not healthy because they use a lot of pesticides. So, I grow my own produce or buy from my neighbors." F1.

3.2.2.2 Category: challenges in grocery shopping activities

Family members described difficulties in making healthy choices at the grocery store, not only due to a lack of knowledge as previously mentioned, but also because of marketing campaigns. They feel confused by the extensive advertising of 'light' and 'healthier' products, which are often more prominently displayed. The variety of these products, coupled with the suspicion that some may not be as healthy as claimed, complicates their choices and reflects their concerns about changes in food processing and ingredients. Additionally, they reported several difficulties in interpreting food labels, particularly due to the small print size.

> "Every time I go to the grocery store, I see so many yogurts, and I get confused. The doctor said the one I bought was a false 'light' yogurt, and others I've tried seem to have a lot of something like sugar... it cannot be healthy. Now, I only eat natural yogurt, but I do not like it." F4.
> "In my time, yogurt was made from milk. Nowadays, there are a lot of different ingredients mixed in." F3.
> "I try to read the food labels to help my wife buy healthy food, but I cannot read them. The letters are too small … "F2.

3.2.2.3 Category: physical activity infrastructures

Family members described poor infrastructure conditions for physical activities in their social context, which become more evident during the winter.

> "… here we do not have enough places to do exercise in winter, and it is always raining. I practiced swimming, but in the swimming pool it was too cold… and I had a flu… so I gave up… maybe in the summer I return my walkies with my husband or we return" F4.

3.2.3 Theme 3: communication challenges

3.2.3.1 Category: barriers to communication between family and healthcare providers

Family members expressed difficulties in communicating with health professionals due to contradictory information they provided. They felt lost and confused by the differing advice provided by healthcare professionals regarding healthy lifestyles. Furthermore, they find it difficult to question the doctor about issues that bother them regarding support for the diagnosed person. They also mentioned that using medical and technical terms does not help them.

> "…the doctor said I have diabetes, but the pharmacist said that with my wife's blood sugar values, she does not have diabetes." F3.
> "…we received so many different pieces of advice from nurses, doctors, and pharmacists. I do not know what to do. Then there's the endocrinologist at the hospital... with which values can I say my father is diabetic? The nurse said my father has good glucose values, but the endocrinologist said to continue the rigorous diet." F5.
> "…the doctors start using those technical terms, and I get confused and cannot ask anything." F2.

3.2.3.2 Category: barriers to family members communication

Family members expressed difficulties in communication within family members. They reported some difficulties in discussing disease management with their relatives without being misunderstood.

> "... sometimes it is not easy to talk to her about her food choices." F2.
> "…he is my father, so I have to respect him... but he does not listen to my advice about diabetes." F3.

3.3 Integration of results

The analysis of findings from each methodology allowed us to identify convergent points of the scoping review and focus group results that were gathered in five main themes (Figure 4). Integrating both results was crucial for a comprehensive understanding of the complex dynamics of diabetes management. The five themes provided a multifaceted perspective that combined broad literature findings and, personal experiences from those directly involved. The scoping review offered a systematic overview of existing research, highlighting key areas and gaps in knowledge, while the focus added the perspective of lived experiences, challenges, and needs of families supporting adults with diabetes.

The themes comprised: (i) "Communication and emotional expression within families" is supported by three categories: family members' communication and challenges, gender differences, barriers to family members communication (ii) "Influence and impact of diabetes management on the family comprised" comprised two categories: impact of diabetes diagnose and management on family members, and family adjustments for diabetes care; (iii) "Diabetes-specific knowledge and education" that is supported by one category identified from scoping review and focus group results: family members' diabetes-specific knowledge; (vi) "Impact and influence of socio-cultural and environmental contexts on diabetes management" that is supported by four categories: barriers to adhering to healthy lifestyle; availability of healthy food choices; challenges in grocery shopping activities, and challenges in grocery shopping activities (v) "Healthcare providers and family members communication is supported by two categories: communication/ interactions between family and healthcare providers, and barriers to communication between family and healthcare providers (Figure 4).

Regarding the first theme, "Communication and emotional expression within families," results from both phases identified several difficulties within the family related to communication and emotional expression. Communication and interactions among

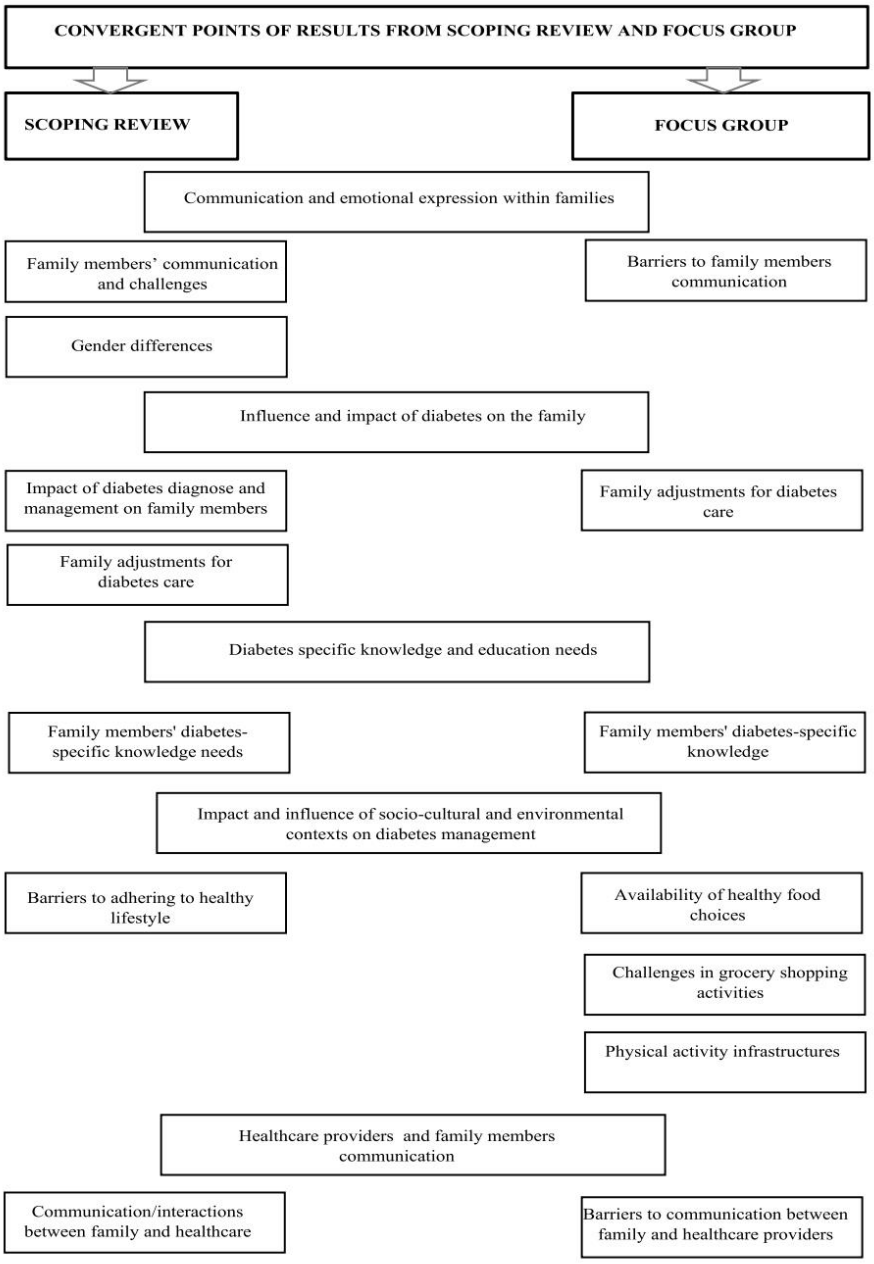

FIGURE 4
Integrating insights: convergent points and key findings from scoping review and focus group.

family members were reported as difficult, often leading to disruptive behaviors such as conflict and arguments over diabetes self-management activities. The differences and difficulties in communication patterns based on gender roles within the family were also emphasized. Family members did not perceive the existence of a supportive environment where they could openly express their emotions and provide mutual support. They reported feelings of confusion about their relative's health status and felt that the diagnosed person did not recognize their role.

The theme "Influence and Impact of Diabetes Management on the Family" encompassed the category of the "impact of diabetes diagnosis and management on family members" reported in the scoping review results and the "family adjustments for diabetes care" (reported in both phases results).The findings highlighted the significant negative impact that a diabetes diagnosis has not only on the diagnosed adult but also on family members. The responsibilities involved in supporting the diagnosed person were identified as sources of emotional stress, anxiety, and burden for the family. Additionally, family members face various adjustments in their daily lives to support the management of the disease, prevent its progression, and avoid complications, alongside the financial problems imposed by the illness. These combined factors—the emotional and physical strain of caregiving responsibilities, daily life adjustments, and financial pressures—negatively impact family members' emotional well-being and physical health over time. An important factor to highlight, and that should be the focus of attention for professionals, is the decision of family members not to get involved in diabetes management, or their refusal to adopt the restrictions imposed by disease, even if the diagnosed person expresses a desire for their involvement.

The theme "Diabetes-Specific Knowledge and Education" was reported in the results of both phases. The findings encompass all difficulties related to how family members process and understand health information provided by professionals, specifically focusing on diabetes knowledge and education about disease management. A lack of diabetes-specific knowledge was identified, as well as a need for more education to improve their skills and abilities to support the diagnosed person.

The "Impact and influence of socio-cultural and environmental contexts on diabetes management" was another theme that emerged from results. If the family is influenced by the diagnosis of diabetes, as has been described throughout this study, the importance of the impact of the different contexts in which the family is embedded is undeniable. All external circumstances related to the availability of healthy food and the existing infrastructure for physical activity can act as facilitators or barriers to the family's adherence to a healthy lifestyle. Thus, in this study, several difficulties and barriers were reported by family members in their daily lives, including a lack of healthy food choices, difficulties in selecting appropriate items in grocery stores, and inadequate conditions for practicing physical activity. These factors significantly negatively influence the daily diabetes management activities and impact the overall health and well-being of family members.

The theme "Healthcare providers and family members communication" was reported in the results of both study phases. In this category, family members reported a lack of time with health professionals, confusion due to the information provided, and contradictory advice received during different consultations. They felt lost and confused by the varying recommendations given by health professionals regarding healthy lifestyles. Additionally, they experienced difficulty in addressing concerns with the doctor about supporting the diagnosed individual. They also mentioned that the use of medical and technical terms was unhelpful.

4 Discussion

Adults' diabetes self-management is a crucial aspect of disease management and typically occurs within a family and social environment (32). Therefore, the various forms of support that families provide to adults with diabetes (e.g., instrumental, social, and emotional) significantly impact diabetes outcomes (10).

Family members' involvement in diabetes management and interventions is complex and should involve more than increased family member-specific diabetes knowledge as a strategy to improve diabetes control and patient diabetes self-care (33).

It is very valuable that family members can perceive and effectively play their role in successful disease management. This involves understanding how to provide emotional, instrumental, and practical support to their relative with diabetes (34, 35). Equally important is their ability to recognize and use other sources of social support, such as community resources, support groups, and healthcare professionals, when necessary (36).

The family's role in reinforcing and maintaining the patient's behavior change is crucial. Literature shows that ignoring this factor could explain the failure of some diabetes family interventions (37).

Family support and involvement in diabetes management should be identified and understood through a comprehensive approach that allows a structured analysis of family dynamics, developmental stages, and functional roles within the context of diabetes (10). Thus, this study, which assessed families using a theoretical model combined with both methodologies (scoping review and focus group), provided a comprehensive framework for understanding the real challenges and needs experienced by families (22).

Family interventions are mostly focused on the outcomes at the individual level and on the overall well-being of the patient (10). Although some studies have assessed the impact of diabetes on family members, the overall impact of diabetes on families is often overlooked (7).

The findings of this study demonstrated the complexity of the construct under analysis and the factors that can affect it. Therefore, both study phase results demonstrated the negative impact on the well-being of family members of emotional dynamics within the adult diagnosis. Family members expressed anxiety, burden, and lower quality of life associated with the higher responsibilities regarding diabetes management (14, 26, 28–31). Family members also reported feelings of exclusion by healthcare providers or the patient, indicating their important role in disease management was not recognized (25, 28, 30). Additionally, their inputs were often overlooked, and they felt unable to influence the diagnosed person.

Family members described these emotional responses, coupled with the low level of diabetes-specific knowledge and education, in both study phases. Furthermore, family members described this as significantly impacting their ability to assist effectively with disease management, as described by other authors (14, 26, 30, 34, 37).

Findings suggested that the emotional dynamics within the family, such as the emotional, psychological, and practical burdens placed on

family members, can increase when the diagnosed person's individual needs conflict with those of the family (28, 29, 37).

Different authors have recognized and demonstrated the importance of family relationships and communication patterns (4, 34, 37, 38). Therefore, positive communication within family can encourage the adult with diabetes on lifestyle modification (4). Conversely, the presence of disruptive family behaviors described have impacted in the well-being of family as described above. These findings align with other studies' results that highlighted the importance of family relationship quality and communication patterns in improving the well-being of all family members (3, 37, 39). Additionally, these authors noted that interpersonal conflicts and miscommunication can arise when family support is perceived as paternalism and criticism, depending on how the support is communicated and provided. Another important topic that emerged in this study is gender difference in communication based on family roles. Women's communication patterns were more assertive, while men tended to give orders (25). This can be explained by the traditional responsibilities of women within the family, which are closely linked to their role in taking care of others, especially when a relative is living with diabetes (38).

Developing a supportive role in assisting the adult with diabetes, family member will be exposed to a series of changes in their daily life, starting with practical adjustments required to maintain family well-being. These include integrating changes into their routines and habits. Over time, the impact on family members extends beyond their emotional and psychological well-being, affecting their physical health and overall well-being (27–29, 31).

One topic highlighted by this study is that the presence of someone (family member/friend) in the daily life of an adult with diabetes is not necessarily synonymous with being a source of support. A family member, feeling affected in some way by the diabetes diagnosis, may decide to remain uninvolved in diabetes management and its associated restrictions (25).

The family economic factor also emerged in the findings of this study (29). These authors describe the burden caused by financial problems related to diabetes diagnosis. The literature describes similar results, emphasizing the associations between a lack of family resources and the negative impact on maintaining healthy behaviors and diabetes management outcomes (40, 41). Other authors reported similar findings, which note that individuals with diabetes and low income are less likely to take their medication due to financial concerns with other necessities, such as paying bills (10).

The environmental factors, whose importance in the prevention and control of noncommunicable diseases has been highlighted in international literature, were also described in the results of this study (5, 42). The environmental barriers described included the lack of accessible places to buy healthy food and safe spaces for physical activity, which significantly reduces the ability of families to maintain healthy behaviors (28, 29). The scarcity of healthy food options implies an effort from families to provide nutritious meals for effectiveness. Similarly, the absence of convenient and safe locations for physical activity limits opportunities for regular exercise, which is vital for controlling blood sugar levels and overall health (5, 42).

The societal discrimination against individuals with diabetes was described in one study included in the scoping review (28). This can exacerbate the challenges faced by families with an adult with diabetes and can reduce the community support available for them (5). In addition, the discrimination can lead to feelings of isolation and frustration, which are usually extended to the work environment, as described in the literature (43). Other studies also described these results (40, 41). These challenges experienced by family members could explain the needs expressed by them in this study's results, which included the presence of a psychologist in diabetes management, as well as the need for more education about the disease and its complications through peer support (29, 30).

The lack of social support is described as a factor that is associated with the worst diabetes outcomes. Therefore, since sources of support are not always available or accessible on a day-to-day basis and may not provide sufficient support to meet the needs of families in managing diabetes, the importance of training and peer support becomes crucial. Peers emerge as individuals who experience the same daily challenges and experiences, and can offer additional social and emotional support that is helpful in dealing with daily diabetes challenges (34, 44, 45).

Considering all the factors described above, addressing the emotional needs of families and supporting their involvement in diabetes-related activities is essential to enhance family support and achieve better outcomes for both patients and their families. Beyond acquiring knowledge and perceived ability to support their relatives, family members may benefit more directly from being actively involved in diabetes management and interventions. This involvement should reduce their stress related to the disease and its complications while also improving their own health behaviors.

4.1 Limitations

Regarding the limitations of this study, the following should be noted: the guiding script for the focus group was not checked in a pretest, and the transcripts from the focus group were not returned to participants for comments and/or corrections. Another limitation is the reliance on data from only one focus group, which may not fully capture the diversity of experiences and perspectives among all family members involved in diabetes management. Additionally, the decision to include only studies published from 2017 onwards in the scoping review, while intended to reflect recent advances in clinical guidelines, family-centered interventions, and technological developments, may have excluded valuable insights from earlier studies. The impact of diabetes on family members is a long-standing issue that transcends temporal and technological boundaries, and excluding older studies might have limited the comprehensiveness of the review. Future research could address these limitations by incorporating a broader temporal scope in literature reviews and ensuring a more robust methodology in the qualitative components of the study. Another limitation of this study is the absence of a distinction between type 1 and type 2 diabetes among the focus group participants. This may have impacted the breadth of insights collected and constrained the exploration of challenges unique to specific types of diabetes, particularly those associated with type 1 diabetes and insulin therapy management.

4.2 Recommendations

This study comprised two phases, providing a comprehensive understanding of the needs and challenges faced by family members

of an adult with diabetes. Healthcare providers should create a supportive environment that enhances the well-being of both adults with diabetes and their family members, leading to more effective diabetes management and improved health outcomes. The development and implementation of tailored diabetes education programs for both the adults with diabetes and their relatives should be based on the holistic assessment of specific needs and strengths within the family, encompassing physical, emotional, social, and economic factors.

By addressing the multifaceted aspects of family dynamics and support, these interventions can foster better communication, stronger emotional support, and more effective management strategies, ultimately improving the quality of life and health for all involved. Future studies should consider conducting separate focus groups for families managing type 1 diabetes and type 2 diabetes. This approach would enable researchers to comprehensively explore the unique needs, challenges, and dynamics associated with each type of diabetes. By doing so, tailored recommendations and interventions could be developed to better support families in managing the specific demands of T1D, such as insulin therapy and glycemic variability, as well as the long-term lifestyle modifications often emphasized in T2D management.

5 Conclusion

In this study, the careful planning and systematic integration of the scoping review results and focus group findings allowed us to create a comprehensive article that offers valuable insights drawn from both literature and lived experiences. This approach provided a deeper understanding of family dynamics from different perspectives and highlighted the specific needs of family members, thereby enhancing the robustness of our conclusions.

It is crucial for professionals to recognize the significant role families play in managing the disease of an adult with diabetes, along with understanding the family as a unit of care, and the specificities of diabetes management. This recognition should lead to the active involvement of family members in care planning and decision-making processes.

Based on this knowledge, practitioners should develop more effective and tailored interventions to improve support for diabetes management while simultaneously promoting the overall well-being of the entire family.

Data availability statement

The original contributions presented in the study are included in the article/Supplementary material, further inquiries can be directed to the corresponding author.

Ethics statement

The studies involving humans were approved by Ethics Committee from Alto Minho Local Health (Decree-Law No 97/95 of 10 May, revised by Decree-law No 8072018 of 15 October). The studies were conducted in accordance with the local legislation and institutional requirements. The participants provided their written informed consent to participate in this study.

Author contributions

VS: Conceptualization, Data curation, Formal analysis, Investigation, Methodology, Validation, Writing – original draft, Writing – review & editing. SL: Data curation, Formal analysis, Investigation, Methodology, Writing – review & editing. CS: Conceptualization, Methodology, Supervision, Writing – review & editing. CM: Conceptualization, Methodology, Supervision, Writing – review & editing. MB-F: Conceptualization, Methodology, Supervision, Writing – review & editing.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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Supplementary material

The Supplementary material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fpubh.2024.1473723/full#supplementary-material

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CAPÍTULO V. MODELAÇÃO DO PROCESSO E DOS RESULTADOS ESPERADOS

Este capítulo aborda a fase de modelação do processo e dos resultados esperados, conforme preconizado pelo modelo de Intervenções Complexas da Medical Research Council. Esta etapa desempenha um papel fundamental no desenvolvimento de intervenções robustas e efetivas, possibilitando testar e refinar os seus componentes antes da implementação, de forma a garantir a sua aplicabilidade e a maximizar o impacto na gestão da diabetes.

O capítulo integra três artigos que ilustram as diferentes dimensões desta fase de modelação. O primeiro artigo descreve a adaptação linguística e cultural e a validação *do Family and Friend Involvement in Adults' Diabetes* para a população portuguesa (FIAD-PT). Este instrumento, selecionado em estudo anterior pela sua robustez psicométrica, revelou-se uma ferramenta fiável para avaliar o envolvimento familiar na gestão da diabetes em adultos. O FIAD-PT será um dos instrumentos utilizados para avaliar a efetividade do programa de intervenção *Juntos com a Família + Capazes*. O segundo artigo, de natureza qualitativa, detalha o desenvolvimento do programa de intervenção, seguindo as fases estabelecidas pelo modelo MRC. A validação conceptual do programa, apresentada no terceiro artigo, foi realizada através da metodologia de grupos focais, permitindo ajustar e aperfeiçoar a estrutura da intervenção com base nas necessidades e perspetivas dos principais intervenientes.

Por fim, o capítulo apresenta o guião de implementação do programa para os profissionais de saúde, o que representa um passo essencial para a aplicação prática desta intervenção. Esta estrutura detalhada visa assegurar que o programa seja implementado de forma consistente e efetiva, promovendo uma abordagem colaborativa e centrada na família na gestão da diabetes.

ARTIGO: *Cultural Adaptation and Validation of the Family and Friend Involvement in Adults' Diabetes (FIAD) Scale for Portuguese Population* – **Artigo submetido para publicação**

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Validation of the Family and Friend Involvement in Diabetes Scale for Portuguese

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Title: Validation of the Family and Friend Involvement in Diabetes Scale for Portuguese

1. Introduction

Diabetes Mellitus (DM) is a growing public health challenge and a global burden involving persons with diabetes, their families, communities, and health systems. [1] The substantial increase in prevalence and the risk of patients developing several complications show that diabetes must be taken seriously by patients and also by healthcare professionals and decision-makers. [1]

Diabetes management requires the adoption of a healthy lifestyle and blood glycose control in addition to adherence to a medication regime. Most of these activities occur in the family environment and usually imply breaking with cultural and family patterns. [2] Consequently, diabetes self-management is directly related to family members' health behaviors, the interdependence established between them, its specificities, and the value of culture for its members. [2]

It is undeniable that family and friends are an important source of instrumental and emotional support for diabetes management and daily disease challenges. [3-5] Family involvement in diabetes interventions and disease management activities have been highlighted as a determining factor for the success of both, with improvements in several clinical diabetes outcomes and family support behavior. [4,5]

However, family involvement in diabetes management can have positive and negative effects, depending on members' actions and intentions. [2,3] Therefore, literature has emphasized the need to distinguish two common types of family involvement, helpful and harmful involvement, which usually occur simultaneously and are positively correlated.[9]

Helpful involvement includes family actions that intend to simplify patients' efforts to improve diabetes management, namely helping patients remember medications or shopping for healthy foods. [2] Conversely, harmful involvement is multidimensional and comprises "miscarried helping" and sabotaging. Miscarried helping consists of family members' behaviors that intend to help with diabetes management and to be supportive. However, this behavior can decrease the patients' self-efficacy and may cause interpersonal conflict and adherence reduction. Sabotaging includes family members' behaviors, who have the knowledge but do not help the person with diabetes with their self-care behaviors. [3] That is, their knowledge is insufficient to motivate them to make lifestyle changes or to perform supportive behaviors. [6-8]

Relevant to this purpose, researchers and health professionals should increase their knowledge about both types of family involvement in diabetes management through a validated instrument specifically developed with this aim. That is the case of the Family and Friend Involvement in Adults' Diabetes (FIAD). [3]

Portugal presents one of Europe's highest DM prevalence rates, with 13.6% of people aged between 20 and 79 years. [9,10] Diabetes is a public health priority in the country, management strategies. [9] Evidence highlights the importance of promoting family involvement, making the assessment of both helpful and harmful dimensions crucial for researchers and health professionals. [3, 6]

This study aimed to culturally adapt and validate the FIAD instrument, to assess helpful and harmful family/friends' involvement in Portuguese adults with diabetes self-management, and examine its psychometric properties.

2. Methods

FIAD is a measurement instrument developed in English that aims to measure both ways of family involvement in diabetes self-management: helpful and harmful family/friends' involvement. [3,6] It allows to generate two separate scores representing the frequency of each type of received support: helpful involvement through nine items (items 1,3,4,7,8,10,11,14,16) and harmful through seven items (items 2,5,6,9,11,13,15). It comprised 16 items that assess observable actions relevant to the respondent's diabetes self-care activities in the prior 30 days.

To culturally adapt and validate FIAD for European Portuguese, we followed good practice principles for culturally adapting health outcome instruments to other linguistic contexts and the COSMIN taxonomy. [11,12] We tested the reliability (internal consistency and reproducibility) and validity (content and construct) of the obtained Portuguese version.

Ethics approval was obtained from the Ethics Committee of Alto Minho Local Health (Decree-Law No 97/95 of 10 May, revised by Decree-law No 8072018 of 15 October), and permission to use and validate the FIAD for the Portuguese population was obtained from the original authors.

2.1. Cultural adaptation

The original measure FIAD was translated into Portuguese by two independent translators, native Portuguese speakers proficiently fluent in English. [3] One of them was a researcher in the field of health and family, the content area of the FIAD construct, and the other was knowledgeable about the cultural and linguistic nuances of the FIAD. A third Portuguese speaker and independent translator then compared both Portuguese versions to analyze any discrepancies in words, sentences, and meanings.

This Portuguese version was back-translated by two independent native English translators with similar qualifications and backgrounds. A multidisciplinary committee, which included a member of the research team, one nurse trained to provide personalized care to adults with diabetes and their families, and three of the four translators used in the previous translation process, then compared these two versions to the original version.

2.2. Pilot test

The pre-final version was administered to a convenience sample of adults (over 18 years) with diabetes. The patients were asked about FIAD content validity, namely the relevance of the construct of interest, comprehensiveness, and comprehensibility of the instructions, items, and response format. [13] In accordance with good practice principles, the researchers established that items with a score of unclear by at least 20% of the sample should be re-evaluated. Similarly, a convenience sample of eight health professionals was asked about FIAD content validity, namely instrument relevance and comprehensiveness. [13]

2.3. Participants

To validate the Portuguese version of FIAD, we created a questionnaire, and from March to August 2023, another convenience sample was recruited from seven primary healthcare units and outpatients from the Endocrinology Department of one public hospital. The

patients were approached face-to-face by a researcher in the hospital department and by their nurses in the primary health care units. In accordance with the Helsinki Declaration, eligible participants were provided with a written informed consent document with the study information, what their involvement encompassed, and other key elements they needed to make a decision on whether to volunteer for the study research.

This study included adults with diabetes (over 18 years) proficient in Portuguese, with no intellectual disability or psychiatric disorders. Pregnant women were excluded. All participants were also informed about their voluntary participation and the possibility to refuse participation in the study, the anonymity and confidentiality of the information, and how the results would be communicated.

2.4. Measurement instrument

The questionnaire implemented consisted of four parts: (i) information about sociodemographic details of the person with diabetes, including sex, age, education level, and employment status; (ii) family information, including number and age of family members in the same household, who provided support to the diagnosed person; (iii) clinical information of the person with diabetes, including duration of diabetes diagnosis, therapeutic treatment, and adherence to non-therapeutic diabetes treatment; and (iv) the FIAD questionnaire.

2.5. Reliability

The reliability of the Portuguese FIAD version was assessed through internal consistency and intertemporal stability. Internal consistency was tested through Cronbach's alpha coefficient, where accepted values should be between 0.70 and 0.90. [14] On the other hand, intertemporal stability was measured by the intraclass correlation coefficient (ICC), with two consecutive moments one month apart. We followed the criteria that a weak correlation corresponds to an ICC lower than 0.50, a score between 0.50 and 0.75 and between 0.75 to 0.90 correspond to a moderate and good correlation, respectively, and a score higher than 0.90 corresponds to an excellent correlation. [11]

2.6. Validity

Content validity was checked during the cultural adaptation and pre-test. Moreover, construct validity was tested by both structural validity and hypothesis testing with samples of sociodemographic, support, and clinical variables.

To test structural validity, we performed both exploratory and confirmatory factor analyses. The former was based on principal components estimates with a previous assessment of the sampling adequacy via the Kaiser–Meyer–Olkin (KMO) indicator and by using Bartlett's test of sphericity. A KMO smaller than 0.50 or between 0.50 and 0.60 is considered unacceptable or poor, and if between 0.60 and 0.70, fair; 0.70 and 0.80, average; between 0.80 and 0.90, good, and if higher than 0.90, very good. The significance of the Bartlett sphericity test should be smaller than 0.001. [15]

To assess the model fit, we also performed a confirmatory factor analysis, considering the following thresholds: comparative fit index (CFI) ≥ 0.90; root mean square error of approximation (RMSEA) < 0.05; and standardized root mean square residual (SRMR) < 0.08. [16] Based on the potential for a shared source of variation, we also correlated error terms.

The hypothesis testing was performed with sociodemographic (sex, age, education, employment status), support (living alone and support from family and others), and clinical variables (diabetes duration, treatment with insulin, diet, and physical exercise)

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variables. Student's t-test was used for two independent variables, and ANOVA was used for more than two independent variables. The statistical software used was SPSS v28 and AMOS.

3. Results

3.1. Cultural adaptation

No important discrepancies were found regarding the forward process followed. The content equivalence, specifically the relevance and pertinence of the FIAD items for the Portuguese population, the discrepancies, and disagreements between committee members were resolved. These professionals evaluated, revised, and consolidated both versions concerning format, wording, grammatical structure of the sentence, cultural meaning, and relevance.

3.2. Pilot test

The pilot test sample included thirteen Portuguese adults. Each participant was asked to rate, as clear or unclear, the instructions, items, and response format. Only two of the thirteen participants rated the response format as unclear, so they were asked to provide suggestions on how to rewrite it more clearly. However, following the criteria defined at the beginning of this study, no changes were made to the FIAD pre-final version. The participants were also asked about the relevance and comprehensiveness of the FIAD. All participants considered the FIAD easy to understand and relevant for the patients with diabetes and their family/friends. They also thought that FIAD included the relevant aspects of family/friends' involvement.

In addition, health professionals were asked about the relevance and comprehensiveness of the FIAD pre-final version. All expert group members described the instrument as relevant for the target population and considered that FIAD included the key dimensions of the construct under evaluation.

3.3. Sample

Our sample consisted of 220 diabetic patients. Table 1 presents the sociodemographic and clinical characterization of the sample.

Table 1 about here

In general, our sample was composed of males (54.3%) and individuals older than 65 years (70.5%) who had primary level education (71.9%) and were retired (73.3%). Most of them lived at home with, at most, two other people (82.3%) and, for diabetes management, felt having some sort of support from family or other significant person (85.3%). Despite the assurances given by the researchers regarding the confidentiality of the data collected, 10 (4.5%) respondents decided not to provide any sociodemographic information.

Concerning the clinical characteristics, this same Table shows that the individuals from our sample had their diabetes diagnosis for a mean of almost 13 years, were mainly taking oral antidiabetics (69.9%), and a significant percentage (15.7%) combined oral medication with insulin. Only about 20% did not follow any type of diet, and 57.1% did not practice any physical exercise.

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Table 2 presents the distributions of the answers for the 16 items of the FIAD questionnaire.

Table 2 about here

As mentioned before, nine of these items correspond to helpful behaviors from family members and friends, and the remaining seven items to a harmful involvement. From this Table, we notice that the most helpful behavior corresponds to asking how they can help with their diabetes (5.49). Other most helpful behaviors include preparing or planning healthy foods (2.90), gently talking with the patient about taking care of diabetes (2.87) and praising the patient for eating healthy foods or following an exercise routine (2.62). However, among harmful involvements, from our sample, we may include arguing with the patient about food choices or their health (2.53) or pointing out in front of others when eating unhealthy foods (2.12).

3.4. Reliability

Table 3 presents the results from intertemporal stability and internal consistency tests. ICC scores were 0.946 for helpful and 0.944 for harmful. For both dimensions, the corresponding 95% CI were also high. Moreover, the internal consistency Cronbach's α for the total FIAD score was 0.893, from 0.773 (harmful) to 0.887 (helpful).

Table 3 about here

3.5. Structural validity

As this study validated a measurement instrument in a different language and for a different culture, we decided to perform both an exploratory and a confirmatory factor analysis.

The KMO measure of sampling adequacy was 0.901 (very good), and Bartlett's test of sphericity was associated with a significance value smaller than 0.001. Table 4 shows the loading scores of the varimax rotated component matrix.

Table 4 about here

We found evidence of the two major dimensions proposed by the authors. Both dimensions explain 49.7% of the variance.

Later, we performed a confirmatory analysis with the corresponding graph presented in Figure 1 to reinforce the structural validity.

Figure 1 about here

As we can see from this figure, we were able to confirm the nine helpful and the seven harmful items. All fit statistics revealed a good fit: CFI=0.993, RMSEA=0.023 [0.000,0.045], SRMR=0.076.

3.6. Hypothesis testing

To complete the construct validity, we analyzed the behavior of both helpful and harmful dimensions regarding sociodemographic, support, and clinical variables. Table 5 presents the results of the tests used.

Table 5 about here

We may conclude that, regarding the sociodemographic variables, only age seems to be a determinant for harmful construct (p=0.002), but not helpful, especially for individuals between 65 and 74 years old.

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Naturally, support variables have a more relevant role for helpful and harmful family and friend involvement in the management of diabetic individuals. In fact, living alone is a determinant for helpful (p=0.007) and harmful (p=0.014). Likewise, having support from family and friends are important for both helpful (p<0.001) and harmful (p<0.001).

Finally, practicing physical exercise has an influence on the helpful dimension (p=0.013).

4. Discussion

To our knowledge, this is the first adaptation and validation of FIAD to another context and language. The decision to culturally adapt and validate the original FIAD in Portuguese adults with diabetes was based on its contents and the results of its psychometric characteristics and on the possibility of assessing both harmful and helpful dimensions of family involvement. [3]

Previous studies independently assessed supportive and obstructive family behaviors and conceptualized them as a unidimensional construct. Nevertheless, assessing and recognizing both harmful and helpful behaviors of family/friends' involvement in diabetes management appeared to be more important than the degree of family involvement in daily activities for diabetes. [6,17]

The findings of this study confirmed, through structural validity assessment, two major dimensions of FIAD (harmful and helpful), as proposed by the original authors. [3] The exploratory and confirmatory analysis also corroborated nine helpful items and seven harmful items described in each dimension of the original instrument, with good fit.

The internal consistency for FIAD total score and for both dimensions was calculated using Cronbach's alpha coefficient. Satisfactory values were found, suggesting that the Portuguese version of FIAD is a reliable measure. [18] The results obtained for the helpful involvement dimension (α = 0.887) and the harmful involvement (α =0.773) were similar to the original version. [3] The test-retest reliability was calculated and showed good intertemporal stability from baseline and approximately three weeks follow-up: the ICC scores for helpful and harmful involvement were, respectively, 0.946 and 0.944).

Regarding FIAD Portuguese version content validity, our sample findings showed positive feedback from the patients and professionals, both participants of this study, which confirmed the importance of health professionals understanding the family involved and its impact on diabetes management.

The pilot test allowed us to understand more deeply how people with diabetes understand their family/friends' behaviors regarding disease management, but also their need to maintain their independence, take care of themselves, and make decisions without depending on others. [4]

As follows, this study results showed that the helpful behavior with a higher score was the item "Ask how they can help you with your diabetes?". People with diabetes wanted help, but they also wanted to decide with family and friends how and what they can help with. [4] Patients need to feel they are able to make decisions regarding diabetes without feeling judged by family and friends. This fact was confirmed by the third FIAD item ("…the importance of family and friends talk gently with them about the disease and its management"). Consequently, the highest-scored harmful behaviors were items that included arguing and pointing out in front of others about people with diabetes's unhealthy behaviors or choices (FIAD items two and nine).

It is also essential to recognize that family and friends of the diagnosed person also experience distress related to their family member's diabetes. [19] We also know that family and friends with higher responsibility for diabetes management, and with disease-related disagreements with the patient report higher levels of diabetes impact, frustration and poorer quality of life. [20] In the analyses of sample characteristics, results were in accordance with the report conducted on the Portuguese diabetic population, in which the majority of participants were male and older than 65 years. [9] Thus, the majority of participants had primary level education and also had a source of support from family/friends. Literature showed an association between low education and health disparities, as well as the increased risk of comorbidities mediated by age and diagnosis of diabetes, that can interfere with a patient's ability to perform diabetes self-management. [21] This information, in addition to the complex daily activities that the diagnosis of diabetes imposes on patients and their families, could explain the results described in this study, in which age seems to be a determinant for harmful construct, especially for individuals between 65 and 74 years old.

Other relevant findings included the importance of gender in diabetes management. In Portugal, and more perceptible in traditional families, women tend to be the one to cook and choose the food for all family members. She decides the family's daily meals. This knowledge is relevant to researchers and health professionals to understand how gender differences can interfere with diabetes management, specifically in non-pharmacological treatment. In the interview, some of the participants, mostly men, did not recognize the preparation of healthy meals as a support behavior from their family/wives but an obligation of them. Our findings were similar to those of another study, which suggests that men feel they have no responsibility for meals at home. [22] On the other hand, if the diagnosed person is a woman, she feels that she has to cook what the family members want/like more, even if it interferes with her personal diabetes management needs. [22]

In international recommendations, physical activity is widely recognized as crucial to diabetes treatment and control. [23,24] In Portugal, there is a community-based exercise program for lifestyle intervention in patients with type 2 diabetes called “Diabetes on the Move”, with weekly sessions conducted at local facilities to improve people with type 2 diabetes engagement in physical activity regularly. [25] Nevertheless, concerning physical activity, this study's findings demonstrated that 57.1% of participants were not practicing any physical exercise. These results are comparable with other Portuguese data, in which it was shown that physical exercise decreased with increasing age, with a higher prevalence of diagnosed people who did not practice any moderate-intensity physical activity in the category of 70 and over age. [25] Additionally, physical exercise positively influenced the helpful dimension, suggesting that active individuals may receive praise, support, or assistance from family and friends to facilitate exercise.

In this study, we recognized the use of COSMIN methodology as a strength. However, regarding the sample, we consider it important to continue assessing family/friends’ involvement in diabetes in other studies, with large samples and racial/ethnic and socioeconomic variations. This data would contribute to increased knowledge about what influences family/friends’ involvement. Moreover, it would be necessary to examine the psychometric properties of FIAD more deeply.

5. Conclusion

The assessment of the psychometric properties of the Portuguese version of the FIAD scale (FIAD-PT) evidenced that it is a reliable and valid instrument for assessing helpful and harmful family/friends’ involvement in Portuguese adults with diabetes.

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Tables and Figures

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Table 1. Sociodemographic and clinical characteristics of patients (n = 220)

	Variable	Value	N	%
Sociodemographic characteristics	Sex	Male	114	54.3
		Female	96	45.7
		Missing data	10	
	Age	≤ 64	62	29.5
		65 – 74	73	34.8
		≥ 75	75	35.7
		Missing data	10	
		Min – max	19 – 93	
		Mean ± sd	68.7 ± 12.5	
	Education level	No read or write	6	2.9
		Primary (4 years)	151	71.9
		Secondary (5 to 12 years)	39	18.6
		Bachelor' degree	12	5.7
		Master degree	1	0.5
		Other	1	0.5
		Missing data	10	
	Employment status	Student	1	0.5
		Worker-student	1	0.5
		Employed	42	20.0
		Unemployed	9	4.3
		Retired	154	73.3
		Other	3	1.4
		Missing data	10	
	Live alone	Yes	32	14.5
		No	178	80.9
		Missing data	10	
	With how many people you live	0	32	14.5
		1	104	47.3
		2	45	20.5
		3	17	7.7
		4	8	3.6
		5	2	0.9
		7	1	0.5
		Missing data	1	
	Support from family or other significant person for DM management	No	31	14.8
		Yes, a member of family	165	78.6
		Yes, a significant person	14	6.7
		Missing data	10	
Clinical characteristics	Duration of diabetes diagnosis (years)	Min – max	0 – 57	
		Media ± sd	12.6 ± 10.1	
	Therapeutic treatment	Only diet	12	5.7
		Oral antidiabetic	145	69.0
		Insulin	20	9.5
		Oral + insulin	33	15.7
		Missing data	10	
	Diet	Always follow diet	89	42.4
		Sometimes follow diet	96	45.7
		Do not follow diet	25	11.9
		Missing data	10	
	Physical exercise	Yes	90	42.9
		No	120	57.1
		Missing data	10	
		Min – max	1 – 30	
		Mean ± sd	5.3 ± 4.4	

Note : sd – standard déviation ; Min – minimum ; Max - maximum

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Table 2 – Distribution of the answers for the 16 FIAD items

	How often do your friends or family members…	Never in the past month	Once in the past month	Two or three times in the past month	Once each week	Twice or more each week	Mean
1.	exercise with you or ask you to exercise with them?	158	16	16	16	14	1.69
		71.8	7.3	7.3	7.3	6.4	
2.	point out in front of others when you are eating unhealthy foods, like at a party or get together?	127	40	18	21	14	2.12
		54.5	12.3	11.8	9.1	12.3	
3.	gently talk with you about taking care of your diabetes?	67	29	39	36	49	2.87
		30.5	13.2	17.7	16.4	22.3	
4.	help you decide if changes should be made based on your blood sugar testing results?	88	28	37	32	35	2.54
		40.0	12.7	16.8	14.5	15.9	
5.	bring foods around that you shouldn't be eating?	127	40	18	21	14	1.89
		57.7	18.2	8.2	9.5	6.4	
6.	tell you diabetes is your problem to deal with on your own?	166	19	14	8	13	1.56
		75.5	8.6	6.4	3.6	5.9	
7.	ask how they can help you with your diabetes?	93	25	36	32	34	5.49
		93	25	36	32	34	
8.	suggest things that might help you take your diabetes medicine when you are supposed to?	106	23	30	28	33	2.36
		48.2	10.5	13.6	12.7	15.0	
9.	argue with you about your food choices or your health?	98	16	38	28	40	2.53
		44.5	7.3	17.3	12.7	18.2	
10.	praise you for eating healthy foods or following your exercise routine?	85	33	30	25	47	2.62
		38.6	15.0	13.6	11.4	21.4	
11.	criticize you for not testing your blood sugar?	156	17	18	10	19	1.72
		70.9	7.7	8.2	4.5	8.6	
12.	help you choose healthy foods. by reading food labels or helping you choose from a menu?	93	29	27	27	44	2.55
		42.3	13.2	12.3	12.3	20.0	
13.	criticize you for not exercising?	135	21	21	17	26	1.99

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		61.4	9.5	9.5	7.7	11.8	
14.	prepare or plan healthy foods to help with your recommended diet?	76	21	30	34	59	2.90
		34.5	9.5	13.6	15.5	26.8	
15.	suggest you don't need to take your diabetes medicine?	202	8	4	2	4	1.17
		91.8	3.6	1.8	0.9	1.8	
16.	take on one of your responsibilities, so you can have time to exercise?	148	20	20	9	23	1.81
		67.3	9.1	9.1	4.1	10.5	

Items' names extracted from original version of FIAD (26)

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Table 3 – FIAD reliability scores

	Range	Mean ± sd	ICC	ICC 95%CI	Internal consistency
Helpful	1 – 5	2.4 ± 1.1	0.946	0.907 – 0.969	0.887
Harmful	1 – 5	1.9 ± 0.8	0.944	0.904 – 0.968	0.773

NOTE: sd – standard deviation; ICC – intraclass correlation coefficients

Table 4 – Exploratory analysis – Factor scores

FIAD Item	Helpful	Harmful
7	0.845	.168
10	0.768	.242
3	0.766	.130
8	0.753	.150
12	0.744	.195
4	0.729	.164
14	0.603	.079
1	0.540	.151
16	0.539	.226
6	-0.041	.707
5	0.033	.677
2	0.284	.677
13	0.256	.637
9	0.586	.591
11	0.376	.579
15	0.084	.243
Eigen value	5.129	2.836
% of variance	32.0%	17.7%

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Table 5 – Helpful and harmful scores for different levels of socio sociodemographic support and clinical variables

Variable	Value	N	Helpful			Harmful		
			Mean ± Sd	|t| or F	Sig	Mean ± Sd	|t| or F	Sig
Sex	Masculino	114	2.50 ± 1.09	0.900	0.369	1.90 ± 0.87	0.963	0.337
	Feminino	96	2.36± 1.11			1.79 ± 0.84		
Age	≤ 64	62	2.46 ± 1.10	1.723	0.181	1.94 ± 0.84	6.405	0.002
	65 – 74	73	2.60 ± 1.20			2.05 ± 0.97		
	≥ 75	75	2.27 ± 1.00			1.58 ± 0.68		
Education	≤ Primary	157	2.39 ± 1.08	1.160	0.247	1.79 ± 0.96	1.789	0.087
	> Primary	53	2.59 ±1.18			2.03 ± 0.96		
Employment status	Retired	154	2.46 ± 1.14	0.533	0.594	1.83 ± 0.86	0.515	0.607
	Not retired	56	2.37 ± 1.03			1.90 ± 0.85		
Live alone	Yes	36	2.02 ± 0.96	2.798	0.007	1.53 ± 0.81	2.491	0.014
	No	174	2.53 ± 1.12			1.92 ± 0.86		
Support from family and others	Yes	179	2.59 ± 1.09	6.523	< 0.001	1.92 ± 0.88	3.662	< 0.001
	No	31	1.56 ± 0.76			1.45 ± 0.62		
Diabetes duration	≤ 5	55	2.62 ± 1.16	0.930	0.427	1.93 ± 0.94	0.320	0.811
	6 – 10	44	2.25 ± 1.12			1.89 ± 0.89		
	11 – 15	54	2.45 ± 1.10			1.79 ± 0.81		
	≥ 16	57	2.41 ± 1.05			1.80 ± 0.81		
Treatment with insulin	Yes	53	2.62 ± 1.07	1.369	0.172	1.90 ± 0.87	0.442	0.659
	No	157	2.38 ± 1.12			1.84 ± 0.86		
Diet	Yes	89	2.59 ± 1.23	1.609	0.099	1.72 ± 0.86	1.893	0.060
	No	121	2.33 ± 1.00			1.95 ± 0.85		
Physical exercise	Yes	90	2.66 ± 1.19	2.492	0.013	1.89 ± 0.87	0.625	0.533
	No	120	2.28 ± 1.01			1.82 ± 0.08		

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ARTIGO: *"Building a Family-Centered Intervention for Adults with Diabetes: Theoretical Foundations"* – **Artigo submetido para publicação no *Journal of Family Nursing***

Journal of Family Nursing

Building a Family-Centered Intervention for Adults with Diabetes: Theoretical Foundations of a Psychoeducational Intervention

Journal:	*Journal of Family Nursing*
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TITLE: Building a Family-Centered Intervention for Adults with Diabetes: Theoretical Foundations of a Psychoeducational Intervention

Abstract

Introduction: Diabetes is a complex global health challenge requiring a holistic, family-centered approach. Effective management extends beyond the individual, emphasizing the family's central role. This study developed *Juntos com a Família + Capazes*, a family-centered intervention to support adults with diabetes and their families.

Methodology: Grounded in the Calgary Family Assessment and Intervention Model and the Medical Research Council Framework for Complex Interventions, the program ensures a structured, evidence-based approach tailored to the dyad.

Results: The six-month intervention includes 7 to 12 sessions (60–120 minutes each) for groups of up to 10 participants, structured into seven thematic modules.

Conclusion: This adaptable program enhances diabetes management and well-being by actively involving both adults with diabetes and their families. Its evidence-based framework enables tailored adaptation to individual, familial, and contextual needs. By positioning family involvement as key, it fosters self-management, shared responsibility, and improved health outcomes.

Keywords: Program development, family, diabetes, adults, mixed methods research

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Background

Globally, diabetes is recognized as a major challenge with complex impacts that affect not only individuals living with the condition, but also their family, healthcare professionals and decision-makers (International Diabetes Federation, 2021). Its wide wide-ranging complications

- personal, social, economic, and burdens on healthcare systems - pose significant obstacles to achieving the United Nations Sustainable Development Goals (World Health Organization, 2023a, 2023b). While effective management can prevent diabetes from being fatal, untreated hyperglycemia exposes individuals to unnecessary risks of severe and potentially irreversible complications, such as end-stage renal disease, blindness, amputations, and ultimately, premature death (International Diabetes Federation, 2021; World Health Organization, 2023b).

For decades, the literature has proposed various strategies and interventions to improve the prevention and control of diabetes and its associated complications (International Diabetes Federation, 2021; World Health Organization, 2023b). However, despite these efforts, data indicate a rising prevalence of diabetes and increase in early mortality associated with this condition, and nurses continue to face challenges in clinical practice, particularly related to promoting adherence to the therapeutic regimen (International Diabetes Federation, 2021; World Health Organization, 2023b).

The demands of being diagnosed with diabetes are described as emotionally, physically, and socially challenging, impacting not only the person but also the family as a whole (Baig et al., 2015; Nascimento do Ó et al., 2022).

This underscores the need for a more comprehensive approach that extends beyond knowledge acquisition to actively involve individuals and their families in the self-management process (Elsayed et al., 2023). Research indicates that simply transferring knowledge does not necessarily lead to sustained behavior change or improved adherence to self-management practices (Thirsk & Schick-Makaroff, 2021).

Therefore, diabetes care interventions must be structured to enhance problem-solving abilities, promote self-efficacy, and encourage shared decision-making between individuals with diabetes, their families, and healthcare providers (Thirsk & Schick-Makaroff, 2021).

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Effective interventions should empower adults with diabetes and their family by strengthening their autonomy in health-related decisions, ensuring that healthcare services align with their actual needs, and address the social, economic, and physical factors that impact their quality of life and overall health (Nutbeam, 2000a; Thirsk & Schick-Makaroff, 2021).

Empowerment enables individuals to gain more control over health-related decisions and actions, with health literacy (HL) playing a pivotal role in this process (Sørensen, 2022; World Health Organization, 1998). As a modifiable factor, health literacy can be improved through diabetes self-management education and support, making it a critical component of effective diabetes care (Nutbeam, 1998, 2000a, 2000b).

However, inadequate health literacy remains a major barrier, as effective management requires individuals and their families not only to understand diabetes-specific information but also to adopt sustainable lifestyle habits and self-care practices (International Diabetes Federation, 2021; World Health Organization, 2017). Low health literacy levels can hinder comprehension of medical advice, adherence to treatment plans, and participation in shared decision-making (Shahid et al., 2022).

To achieve meaningful empowerment, diabetes care strategies must extend beyond providing disease-related education to adopt a holistic approach that integrates healthcare services with broader health determinants (American Diabetes Association, 2023; Nutbeam, 2000b).

Human responses to chronic conditions like diabetes are influenced not only by individual characteristics and behaviors but also by broader social, physical and economic contexts (World Health Organization, 2016, 2017, 2023a, 2023b). Considering these broader influences enables healthcare strategies to better support adults with diabetes in making

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autonomous health decisions and achieving a greater control over their health outcomes (Lee, 2018; Mogessie et al., 2022; Nutbeam, 2000b).

Psychoeducational interventions, which address the emotional, physical, and social dimensions of the disease, have the potential to significantly enhance the quality of life for people living with diabetes. By fostering more comprehensive and sustainable self-management strategies, these interventions create a more effective and inclusive framework for diabetes care psychoeducational interventions have the potential to significantly enhance the quality of life of people living with diabetes (Wichit et al., 2017; World Health Organization, 2023a, 2023b).

This paper aims to describe the development of a psychoeducational intervention titled *Juntos com a Família + Capazes* (Together with Family + Capable) co-designed with adults with diabetes and their family. The intervention program was structered following the optimized development phase of the Medical Research Council's (MRC) Framework for Complex Interventions and based on the Calgary Family Assessment and Intervention Model (CFAIM) (Bleijenberg et al., 2018; Craig et al., 2008; Richards & Hallberg, 2015; Shajani & Snell, 2019).

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Method

This study employs a mixed-methods design, guided by the MRC and CFAIM (Bleijenberg et al., 2018; Craig et al., 2008; Richards & Hallberg, 2015; Shajani & Snell, 2019). Additionally, the development process of the intervention program was structured by the Criteria for Reporting the Development and Evaluation of Complex Interventions in Healthcare (CReDECI), ensuring a transparent, structured, and scientifically rigorous approach to documenting both the intervention's design and evaluation (Möhler et al., 2015). This methodological rigor guarantees that the intervention is both theoretically grounded and

practically applicable, addressing the complexities of diabetes management within a family-centered care model (Möhler et al., 2015).

The integration of the two theoretical models provides a comprehensive and methodologically robust framework, allowing for a systematic and evidence-based approach to intervention development (Bleijenberg et al., 2018; Craig et al., 2008; Richards & Hallberg, 2015). This combined perspective offers a strong foundation for tackling the intricacies of family-centered interventions, which involve multiple interacting components, including individual behaviors, family dynamics, and broader social and healthcare contexts (Bleijenberg et al., 2018; Craig et al., 2008; Richards & Hallberg, 2015).

The following phases were outlined to ensure a structured and iterative development process: (i) definition and identification of the research problem; (ii) Identifying or developing theory (iii) identification of evidence and analysis of current practice and contextual factors; (iv) determine the needs; and (v) modeling process and expected outcomes. Although these phases are clearly conceptualized and well-defined within the framework, their practical application is dynamic and interconnected, allowing for continuous revisions and adaptations throughout the process (Bleijenberg et al., 2018; Craig et al., 2008; Richards & Hallberg, 2015).

Figure 1 about here

1. Research Problem Identification & Definition

A comprehensive understanding of the underlying issue is fundamental to the development of effective interventions, as it ensures that strategies are tailored to address the specific challenges and complexities associated with the condition (Bleijenberg et al., 2018; Craig et al., 2008; Richards & Hallberg, 2015).

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Diabetes and its complications remain top priorities on global health agendas, with the increasing prevalence posing significant risks to the health and well-being of individuals, families, and communities (International Diabetes Federation, 2021, 2023). This growing burden underscores the urgent need for comprehensive and sustainable management strategies that extend beyond clinical treatment to encompass the social, economic, and behavioral determinants influencing diabetes outcomes (Elsayed et al., 2023).

Effective diabetes self-management goes beyond adherence to treatment regimens; it requires informed decision-making, lifestyle adjustments, and active engagement from both the individual and their family (World Health Organization, 2020, 2022b, 2022c). Given that many self-management activities take place within the family environment, family involvement plays a crucial role in supporting disease control and fostering sustainable health behaviors (Tajdar et al., 2021; World Health Organization, 2017).

Consequently, both diabetes care guidelines and the academic literature have increasingly emphasized the critical role of social support, particularly family involvement, in optimizing diabetes management and improving clinical outcome (American Diabetes Association, 2022; International Diabetes Federation, 2021; Zhang et al., 2022).

Addressing these factors requires a holistic and multidimensional approach that not only supports individuals in their self-management efforts but also integrates the family and broader support networks into the care process (American Diabetes Association, 2022; International Diabetes Federation, 2021; Zhang et al., 2022).

However, the literature has emphasized the limitations of some educational interventions that fail to translate increased diabetes-specific knowledge into sustained behavioral changes, as they are often strategies focused almost exclusively on the person with diabetes and planned

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using "top-down" strategies, without actively involving the people directly affected. (American Diabetes Association, 2022; International Diabetes Federation, 2021).

In this context, family-centered interventions have emerged as a promising strategy, acknowledging the pivotal role of family members in providing both instrumental (such as medication management, glucose monitoring, transportation to medical appointments, and meal preparation), and emotional support for individuals with diabetes (McEwen et al., 2019; Mogessie et al., 2022; Zhang et al., 2022). Despite their recognized importance, the integration of families into diabetes management strategies remains inconsistent, often lacking structured theoretical frameworks and standardized methodologies (Author Blinded, 2025). To address these gaps, this study employs a systematic approach to develop a family-centered psychoeducational intervention, ensuring that the proposed strategies are scientifically rigorous, adaptable, and practically implementable in real-world healthcare settings.

2. Identifying or developing theory

In developing complex interventions, identifying evidence and a theoretical framework is a crucial step (Bleijenberg et al., 2018). According to the Medical Research Council, this process ensures that interventions are grounded in established knowledge, linking their components to desired outcomes through causal mechanisms (Bleijenberg et al., 2018). Drawing on existing evidence and theory not only justifies the need for the intervention, but also guides its design, and ensures its practical relevance.

Given the family's essential role in diabetes management, it became evident that nurses and researchers must deepen their understanding of the challenges in educational interventions for both patients and their families, as well as the factors influencing their implementation and effectiveness (Shajani & Snell, 2019; Zhang et al., 2022).

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This intervention program was structured based on CFAIM, which provides a comprehensive framework for assessing the family as a dynamic system. This model marks a significant transformation in nursing care, by positioning the family as a central element in health management, and in this specific situation in diabetes management. By evaluating the structural, developmental, and functional dimensions of the family, CFAIM allow the identification of key areas for targeted interventions, guiding strategies that enhance family engagement and improve health outcomes (Shajani & Snell, 2019). It offers nurses a flexible and evidence-based approach, ensuring that both individual and family needs are addressed in a personalized way (Wright & Leahey, 2013). Beyond merely assessing family dynamics, CFAIM expands the nurse´s role transforming them into facilitator of change, that go beyond the diagnosed person, encompassing the entire family unit (Wright & Leahey, 2013).

This framework has the potential to optimize communication, to improve family conflict resolution, and strengthens mutual support, which are essential elements in diabetes management (American Diabetes Association, 2022; American Diabetes Association, 2023). It contributes to the effectiveness of self-management strategies and promotes sustainable health behaviors, reinforcing the family´s critical role in supporting the diagnosed person (American Diabetes Association, 2023; Pamungkas & Chamroonsawasdi, 2020).

By integrating CFAIM, the intervention program acknowledges the importance of a holistic, family-centered approach in diabetes care. This foundation ensures that interventions are not only evidence-based but also systematically structured and practically applicable, fostering a more comprehensive and sustainable model of care (Shajani & Snell, 2019).

3. Identification of evidence and analysis of current pratice and contextual factors

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Examining current practices in diabetes care is essential to identify gaps and opportunities for improvement (van Meijel et al., 2004). By evaluating how care is currently delivered, particularly with regard to family involvement in diabetes management, healthcare professionals can gain valuable insights into the strengths and limitations of existing approaches (Bleijenberg et al., 2018).

Building on the importance of existing evidence, a review of the literature identified several studies evaluating the effectiveness of family-centered interventions, demonstrating positive effects on various clinical indicators associated with diabetes (Bennich et al., 2019) 2019). These studies highlight that incorporating family support into diabetes management can lead to improved glycemic control, better adherence to treatment regimens, and enhanced psychological well-being among individuals with diabetes (Bennich et al., 2019; Zhang et al., 2022).

Reviewing the literature, several systematic reviews were identified, leading the research team to conduct an umbrella review to synthesize existing systematic reviews on family-centered interventions (Author Blinded, 2024). This review, which included five systematic reviews of varying methodological quality, confirmed the family-focused interventions as beneficial for diabetes management and clinical outcomes. Following the Joanna Briggs Institute (JBI) guidelines, the review synthesized evidence on the effectiveness of family-centered intervention programs for adults with diabetes, covering publications from 2013 to 2024. The umbrella review provided valuable insights into the effectiveness of existing interventions, cultural variations, relevant outcome measures, and the acceptability of various strategies (Aromataris et al., 2015; Aromataris et al., 2020; Author Blinded, 2024). The methodological quality of the included studies was assessed using the Critical Appraisal

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Checklist for Systematic Reviews and Research Syntheses, ensuring a rigorous evaluation process (Aromataris et al., 2015; Aromataris et al., 2020; Author Blinded, 2025)

The umbrella review highlighted the need for structured, theory-based, family-centered interventions that are methodologically consistent and adaptable to the specific needs of adults with diabetes and their families, as well as to the broader contexts in which they live. Despite their proven effectiveness, existing interventions for adults with diabetes and their families exhibit considerable heterogeneity, thereby constraining their replicability and broader applicability across diverse populations and healthcare settings. Furthermore, many programs do not adequately address the dynamic and evolving nature of family roles in diabetes care, posing additional challenges to their adaptability and long-term sustainability (Zhang et al., 2022).

Findings from the umbrella review highlighted family functioning as a key factor in the success of educational interventions, influencing both short- and long-term health outcomes (Mayberry et al., 2019). A well-functioning family not only enhances adherence to treatment but also fosters a more comprehensive and sustainable approach to health management (Pamungkas & Chamroonsawasdi, 2020). Given its critical role, promoting family involvement in diabetes management requires healthcare professionals to recognize the impact of family functioning and assess it using validated instruments (Mayberry et al., 2019). Understanding family dynamics, relationships, and behaviors is essential to ensuring that the support provided is both effective and tailored to the specific needs of adults with diabetes and their families (Mayberry et al., 2019).

Recognizing the gap in validated assessment tools specific to this population, the research team undertook another systematic review to examine the psychometric properties of existing family assessment instruments targeted at adults with diabetes and their families

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(Author Blinded, 2023). This review aimed to identify, evaluate, and synthesize the psychometric properties of existing instruments designed to assess family functioning and involvement in diabetes management. The study was conducted according to the JBI methodology, ensuring a rigorous and structured approach to data collection, analysis, and synthesis (Stephenson et al., 2019). The search strategy encompassed multiple electronic databases, including PubMed, CINAHL, Scopus, PsycINFO, and Web of Science, to ensure comprehensive coverage of relevant literature. Studies were included if they met predefined eligibility criteria: (i) focused on adults diagnosed with diabetes, (ii) assessed family involvement or functioning using a validated instrument, and (iii) reported psychometric properties such as validity, reliability, and responsiveness. The 31 included instruments were then evaluated using the Consensus-based Standards for the Selection of Health Measurement Instruments (COSMIN) criteria, which provided a structured framework for assessing measurement properties, including internal consistency, structural validity, test-retest reliability, and responsiveness (Mokkink et al., 2017; Mokkink et al., 2010). While some tools were disease-specific, others were more general, lacking diabetes-related constructs. This heterogeneity underscores the need for culturally adapted, psychometrically robust, and contextually relevant instruments that can effectively guide family-centered interventions.

Building on the findings of the systematic review, the adaptation and validation of the "Family and Friend Involvement in Adults' Diabetes" (FIAD) was undertaken to ensure a reliable and contextually relevant tool for assessing family involvement in diabetes management (Author Blinded, 2023). The FIAD-PT will serve as a key instrument for evaluating the effectiveness of the intervention program, reinforcing the program's scientific rigor.

Both studies aimed to identify the most effective elements highlighted in the literature, ensuring their integration into the intervention program and the assessment of its effectiveness.

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By incorporating these evidence-based components, the program is designed to establish a scientifically grounded structure that addresses existing gaps, fostering the effective empowerment of individuals with diabetes and their families. This approach seeks to enhance diabetes management by promoting sustainable self-care behaviors and optimizing health outcomes.

4. Determine the needs

The development of a family-centered intervention requires a thorough understanding of the needs, preferences, and capacities of both the adults diagnosed with diabetes and their families (Bleijenberg et al., 2018). This process involves the active involvement of the dyad – adult with diabetes and family – population and healthcare professionals, to ensure that the intervention is tailored to the specific context and challenges faced by those affected. The involvement of all stakeholders, professionals and the target population in this design phase was done with the aim of creating a program that is relevant and effective in addressing the complex dynamics of diabetes management.

Considering the importance of family involvement in interventions and the effective empowerment of the dyad, the literature review conducted throughout all phases highlighted the necessity of recognizing not only the needs and experiences of the person diagnosed but also those of their family. Additionally, it is crucial to consider their social and community resources when developing intervention strategies. To foster positive family support, it is essential to promote engagement in diabetes self-management activities and encourage the adoption of healthy lifestyle habits (Bennich et al., 2019; Thirsk & Schick-Makaroff, 2021).

To comprehensively identify family needs, a two-phase study was conducted. The Phase 1 consisted of a scoping review that mapped gaps in the literature and highlighted the challenges

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faced by families in the context of diabetes. This review was conducted using databases such as MEDLINE®, CINAHL®, SciELO, and PsycINFO, along with gray literature sources from the Scientific Open Access Repository of Portugal and OpenGrey. Following the Joanna Briggs Institute and PRISMA guidelines, eight studies published between 2017 and 2023 were included. Phase 2 involved a focus group with 10 participants, comprising five adults diagnosed with diabetes and their family members. This phase provided an analysis of family dynamics and the factors influencing disease management. Data were analyzed using the Consolidated Criteria for Reporting Qualitative Research (COREQ), ensuring a structured and rigorous approach to understanding family involvement in diabetes care. Results from both phases identified five key themes: communication and emotional expression within families, the impact of diabetes on family dynamics, diabetes-specific knowledge, socio-cultural and environmental influences on diabetes management, and communication with healthcare providers. The findings underscored that, beyond clinical outcomes, addressing the emotional needs of both adults diagnosed with diabetes and their family members is essential for effective disease management. Additionally, family members highlighted the need for greater support from nurses to facilitate their active participation in diabetes care. Such support is crucial for enhancing family engagement and, ultimately, improving health outcomes for both individuals with diabetes and their families (Author Blinded, 2025).

In addition to the research and clinical experience of the research team, meetings with healthcare professionals were conducted prior to the development of the program, ensuring that the intervention program was grounded in both empirical evidence and real-world clinical practice. These discussions provided valuable insights into the practical challenges of diabetes management and the role of family involvement. Additionally, these meetings highlighted the

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difficulties healthcare professionals encountered in recognizing and integrating the family as a unit of care.

This difficulty may arise from the content and focus of ~~undergraduate~~ nursing education, where the concept of the family as a unit of care is not sufficiently explored or practiced (Barbieri-Figueiredo et al., 2021). Despite this, nurses acknowledged the significant role of family involvement and family dynamics in improving health outcomes for chronic diseases, especially diabetes. These gaps in training highlight the need for greater emphasis on family-centered approaches in nursing education, including the development of specific curricula and training programs that equip nurses with the necessary skills to assess and support family engagement in chronic disease management. Strengthening this aspect of nursing education could enhance the ability of healthcare professionals to implement holistic, patient- and family-centered interventions, ultimately contributing to improved diabetes self-management and better long-term health outcomes.

5. Modeling process and expected outcomes

The modeling process aims to optimize key components while managing costs, ensuring both effectiveness and alignment with current practices and contextual needs (Bleijenberg et al., 2018). This phase enables testing and refinement, ensuring the intervention remains adaptable and responsive to the target population.

Within the MRC framework, intervention design and modeling are interconnected, as both involve evidence-based development and theoretical foundations (Bleijenberg et al., 2018). During this phase, core components are structured to meet the population's needs while assessing feasibility and potential effectiveness within the implementation context.

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The validation study of the *Family and Friend Involvement in Adults' Diabetes* (*FIAD*) instrument, previously identified in the earlier phase, was integrated into this stage (Mayberry et al., 2019). Many healthcare professionals, particularly nurses, observed that consultations in clinical settings are primarily centered on the individual, with family assessments rarely conducted. However, the validation study introduced them to family assessment tools, enhancing their understanding of family dynamics and their influence on health outcomes. The study was well received, with professionals acknowledging the instrument's potential for clinical application, particularly in evaluating the effectiveness of interventions designed to improve family functioning.

The FIAD was culturally adapted and validated for the Portuguese population (*FIAD-PT*) using a methodological study involving 220 adults with diabetes, following the *Consensus-Based Standards for the Selection of Health Measurement Instruments* (COSMIN) guidelines (Acquadro et al., 2004; Mokkink et al., 2010; Terwee et al., 2018).

The validation results from exploratory and confirmatory factor analyses confirmed the two core dimensions of family involvement (*harmful* and *helpful*) as proposed by the original authors (Mayberry et al., 2019). The FIAD-PT exhibited strong reliability and validity in assessing the role of family and friends in the self-management of adults with diabetes. Its integration into this study offers a robust tool for evaluating the intervention program's impact on family dynamics, further reinforcing its applicability in both clinical practice and research.

In this modeling phase, the development of the intervention program incorporated insights from previous phases, including the content to be covered and the strategies to be used, ensuring a structured and evidence-based approach

Additionally, the diferent phases findings highlighted the importance of nurses facilitating the program to possess in-depth knowledge of diabetes self-management and

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therapeutic regimens, as well as expertise in motivational interviewing and group-based therapeutic education. The nurse leading the sessions must demonstrate flexibility, continuously adapting their approach to meet specific needs of participants (Author Blinded, 2023; Author Blinded, 2025)

The central goal of the intervention program is to support the empowerment of the dyad—adults with diabetes and their families—by contributing to increased health literacy and enhancing their capacity to make informed decisions about managing their health and disease. This empowerment aims to improve diabetes-specific knowledge, enhance factors that influence diabetes control, and strengthen psychosocial self-efficacy in managing the disease. It also aims to build participants' capacity to address behavioral challenges, including preventive actions and effective disease management. Additionally, the program is designed to improve health-related quality of life, optimize clinical diabetes indicators, and encourage adherence to a healthier lifestyle. Strengthening autonomy, family functioning and self-management capabilities also intends to reduce associated complications and health-related costs, ultimately contributing to the well-being of the dyad and those who depend on them.

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Results

The intervention program was structured into modules, each covering key content identified in previous stages as essential for empowering adults with diabetes and their families to enhance overall health outcomes. The conceptual validation of the program —focusing on its structure, content, and methodology—was conducted through three focus groups (two multidisciplinary groups and one composed of adults with diabetes and their family members). The validation process is described in detail in another study that is under review.

The main elements of the intervention program are briefly outlined below (Table 1); however, a comprehensive manual will be provided to the healthcare professionals responsible for implementing the program. This manual will detail the final structure of the intervention, its modules, and its specific objectives. Additionally, it will specify the expected outcomes and the assessment instruments to be used, ensuring systematic monitoring and evaluation of the program's effectiveness.

Table 1 about here

Target Population: Is defined as the dyad, consisting of an adult (aged 18 years or older) diagnosed with diabetes and their family member. In alignment with the Calgary Model's definition of family, this program considers as a family member any adult identified by the diagnosed individual as their primary source of support—whether instrumental, financial, emotional, or otherwise—in managing diabetes. This definition applies regardless of biological ties or cohabitation status (Wright & Leahey, 2013).

Duration: lasts up to six months.

Number of Sessions: Includes a minimum of seven and a maximum of twelve sessions. The program coordinator may adjust the number of sessions up to the maximum of twelve based on the needs expressed by participants in each module.

Session Duration: Each session is designed to last between 60 and 120 minutes. The exact duration of each session is managed by the coordinating/facilitating nurse according to the group's characteristics and the module's requirements.

Number of Participants per Session: Each intervention group should consist of a maximum of ten participants.

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Session Frequency: Sessions are recommended to be held biweekly to minimize participant burden and reduce transportation costs. However, the coordinating/facilitating nurse may adjust the frequency based on participant needs.

Session Scheduling: In first session (Session Zero), the coordinating/facilitating nurse, in collaboration with the participants, should schedule the dates and times for all sessions. This pre-planning helps participants balance their personal and family commitments with their participation in the program.

Program Structure: The program follows a modular structure comprising seven mandatory modules. It begins with "Baseline Module" and concludes with the "Final Module: Closing Session", which correspond to the pre- and post-intervention data collection points. The time span between these two modules is estimated a maximum of six months.

Modules: The intervention program includes five modules in addition to the “Baseline Module” and the “Final Module”. These five modules are titled:

- Transforming Habits: Pathways to a Healthy Lifestyle in Diabetes Management;
- Balanced Nutrition: A Healthy Approach to Diabetes Management;
- Movement and Health: The Importance of Physical Activity in Diabetes Management;
- Family and Communication: Essential Family Dynamics in Diabetes Mellitus Management;
- Diabetes Mellitus: Understanding, Self-Monitoring, and Overcoming Potential Complications for a Fulfilling Life;

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The coordinating/facilitating nurse, while adhering to the program's guidelines and based on prior participant assessments and ongoing identified needs, may personalize the intervention for each group. This customization includes determining the order of the five modules, adjusting the number of sessions per module, and modifying the duration of sessions according to the content covered and participant requirements.

Session Format: Sessions should preferably be conducted in person at a location that is accessible to participants. Alternatively, the Zoom platform may be used if all group members agree and have the necessary technological resources and digital literacy.

Strategies to use in Sessions: The program incorporates various strategies to enhance engagement and effectiveness, including:

- A combination of traditional teaching methodologies and dynamic group strategies. Active participant involvement in problem-solving and topic discussions within each module is encouraged using verbal content presentations;
- Distance learning approaches may also be employed where appropriate. The feasibility of incorporating digital tools (Zoom or Teams) will be assessed based on group characteristics, including digital literacy, internet access, and device availability;
- Interactive group games;
- Group-based physical activity practice;
- Providing a notebook and pen at the first session so participants can record questions or concerns to be addressed in subsequent sessions;
- Distributing educational materials, such as diabetes management guides for reference and ongoing learning;
- Creating a blog summarizing session topics for participants' reference;

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- Motivational follow-up phone calls throughout the intervention and the six-month post-program period. Healthcare professionals will apply motivational interviewing principles during these. Phone calls will be conducted by the coordinating/facilitating nurse with the adult with diabetes, although arrangements may be made to include family members in these interactions;
- Reflection moments at the end of each session, encouraging participants to share brief feedback on the session;
- Creating private social media groups for post-session experience-sharing and peer support;
- Program Objectives and Expected Outcomes.

While the program outlines recommended strategies for each session, it provides facilitators with the flexibility to adapt these strategies according to the specific characteristics of each group. Additionally, the program suggested the use of social media groups and phone calls between sessions to maintain motivation and engagement of participants.

Expected Results and Health Gains Assessment: Participation in the intervention program is expected to yield various health benefits for both the individual with diabetes and their family, adjusted to the specific needs of each intervention group. Anticipated outcomes include:

- Improved health literacy, particularly regarding diabetes knowledge and self-management.
- Enhanced adherence to therapeutic regimens.
- Greater ability to manage disease-related challenges.
- Increased self-efficacy and overall quality of life.

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- Enhanced family functioning, resulting in stronger support networks and more effective communication among family members.

All variables described will be assessed using validated instruments that have been adapted to each specific context and culture.

Discussion

Diabetes management is a multifaceted challenge that extends beyond individual responsibility, requiring a structured, multidisciplinary, and family-centered approach (American Diabetes Association, 2022; American Diabetes Association, 2023).

In this context, family-centered interventions have emerged as a promising strategy, recognizing the pivotal role of family members in providing both instrumental and emotional support, leading to improvements in both clinical and psychosocial outcomes (Mayberry et al., 2019; Mogessie et al., 2022). However, despite their well- established benefits, the integration of families into diabetes management strategies remains inconsistent, often lacking structured theoretical frameworks and standardized methodologies (Author Blinded, 2025).

To address these gaps, this study employs a systematic approach in developing a family-centered psychoeducational intervention**,** ensuring that the proposed design and strategies are scientifically rigorous, adaptable, and practically implementable in real-world healthcare settings. The intervention program *Juntos com a Família + Capazes* was designed following MRC Framework for Complex Interventions and the CFAIM Model, ensuring both theoretical and methodological robustness (Bleijenberg et al., 2018; Shajani & Snell, 2019). This structured approach enhances its applicability while moving away from the traditional paternalistic

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healthcare mode, replacing unilateral goal-setting with a collaborative and participatory framework (American Diabetes Association, 2023; McEwen et al., 2019).

This intervention program was designed to promote empowerment of adults with diabetes and their families, with emphasis on health literacy promotion, and diabetes self-management. Strengthening these competencies is expected to translate into improved quality of life, greater adherence to the therapeutic regimen, and prevention of diabetes-related complications (American Diabetes Association, 2023). In line with the Ottawa Charter for Health Promotion, and the Sustainable Development Goals**,** the program facilitates decision-making, and the ability to overcome everyday barriers, fostering autonomy and sustainable health behaviors (Ministério da Saúde, 2019; Sachs et al., 2023).

Given their pivotal role in health education, nurses play a crucial role in promoting empowerment, facilitating knowledge-sharing, strengthening support systems, and fostering a co-constructed approach to self-care that is both person-centered and family-inclusive (International Council of Nurses, 2019; International Diabetes Federation, 2021). Rather than imposing predefined solutions, nurses act as facilitators, guiding individuals and families in identifying their own strategies for diabetes management (International Council of Nurses, 2019; International Diabetes Federation, 2021). This participatory approach fosters a supportive environment that enhances self-management, aligns with public health priorities, and contributes to reducing health disparities (Sachs et al., 2023; World Health Organization, 2019, 2022a, 2023a). Furthermore, by recognizing the interdependence between individual and family well-being, the program reinforces the notion that diabetes management is most effective when approached as a shared responsibility, where informed decision-making and collective problem-

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solving lead to sustained health improvements (Sachs et al., 2023; World Health Organization, 2019, 2022a, 2023a).

To ensure a comprehensive understanding of family dynamics in adults with diabetes, this study integrates insights from a systematic review of the psychometric properties of family assessment tools, highlighting the need of validated instruments to assess family functioning in the context of adults with diabetes (Author Blinded, 2023). The Family and Friend Involvement in Adults' Diabetes (FIAD) instrument was identified as particularly relevant due to its ability to measure both helpful and harmful dimensions of family involvement in diabetes self-management (Mayberry et al., 2019). The FIAD instrument, which was culturally adapted and validated for the Portuguese population (FIAD-PT), was incorporated as a key evaluation tool in this study to assess the impact of the intervention program on family dynamics and diabetes self-management (Mayberry et al., 2019). Its inclusion ensures that family support is not only acknowledged but also systematically assessed, reinforcing the scientific rigor of the program (Mayberry et al., 2019).

Since family functioning is a key determinant in sustained long-term diabetes management and adherence to treatment regimens, the Calgary Family Assessment and Intervention Model (CFAIM) plays a critical role in this study (Shajani & Snell, 2019). This model encourages the assessment of structural, developmental, and functional dimensions of family dynamics, helping healthcare professionals recognize that diabetes management is not solely an individual responsibility but a shared process within the family unit. Additionally, this approach acknowledges the moderating effect of family environments on cultural, racial, and socioeconomic factors, which are crucial determinants of diabetes management outcomes (Shajani & Snell, 2019).

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To enhance diabetes care and develop effective interventions, health professionals must consider these determinants, while also incorporating the perspectives and insights of adults with diabetes and their families, who are the true experts in their own health process (Wichit et al., 2017; World Health Organization, 2023b). This inclusive perspective allows for a tailored and holistic approach, addressing not only the medical aspects of diabetes care but also the relational and socio-emotional factors that influence adherence and long-term disease management (Shajani & Snell, 2019). When context constraints, or professional inexperience hinder a structured family-centered approach, the authors of CFAIM propose considering the family as a context rather than a unit of care, focusing on the broader family environment that influences the individual's health (Shajani & Snell, 2019).

The intervention program described in this study differentiates itself by adopting a systematic development process, based on the Medical Research Council's framework for complex interventions, ensuring that the program is evidence-based, scientifically rigorous, while maintaining a flexible design (Bleijenberg et al., 2018; Craig et al., 2008). The structured allows for the customization of session duration, content, and delivery methods, adapting to participants' specific needs, thus optimizing its real-world applicability and impact.

The involvement of a multidisciplinary experts and adults with diabetes and their families in the conceptual validation process provided valuable insights for refining the program. Expert feedback emphasized the importance of ensuring that sessions remain practical and relevant to participants'' daily experiences rather than overly theoretical, aligning with findings in the literature that stress the need for culturally and contextually appropriate interventions (Shajani & Snell, 2019; Wichit et al., 2017).

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To maintain and promote sustained progress in diabetes management, motivational and follow-up calls were integrated into the program (Miller & Akohoue, 2017). This strategy ensures that goals remain clear and actionable, empowering participants to take charge of their health.

Although digital meetings were considered as part of the intervention, their use will be subject to participants' access to digital resources and digital literacy skills. This adaptability ensures inclusivity, mitigating the impact of digital disparities and making the intervention accessible to all, regardless of technological proficiency (Feinberg et al., 2021; Kerr et al., 2019)

The flexibility embedded in the program's design is essential for reducing inequalities in health education and care, particularly in chronic disease management, where sustained engagement and support are critical. Future adaptations of the program should continue to prioritize accessibility, integrating both digital and non-digital options to optimize reach and effectiveness across diverse populations.

Strengths and Limitations

Ensuring the effective adaptation of the intervention to the specific needs of each participant group presents a potential challenge, despite the program's flexible design. While adaptability is a core strength, its successful implementation across diverse healthcare settings relies on the comprehensive and continuous training of facilitators. This training is essential to equip professionals with the necessary skills to personalize the intervention while maintaining fidelity to its core principles and ensuring methodological consistency.

Nevertheless, the intervention program demonstrates several key strengths that reinforce its potential impact. One of its foremost strengths lies in its robust theoretical foundation, which integrates the CFAIM and the MRC framework for complex interventions. This combination

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ensures a rigorous, systematic, and evidence-based approach while supporting a holistic perspective on diabetes management that positions family involvement as a central component. By framing the family as a unit of care, the program acknowledges the multifaceted nature of diabetes self-management, addressing not only clinical needs but also the other determinants that influence health outcomes.

A further strength is the comprehensive conceptual validation process, which incorporated insights from multidisciplinary professionals, adults with diabetes, and their families. This approach enabled an iterative refinement of the intervention, ensuring its structure, content, and delivery align with the lived experiences and specific needs of the target population.

Additionally, the program's modular and adaptable structure facilitates customization of session duration, content, and delivery methods based on the characteristics and preferences of each intervention group. This adaptability enhances its applicability across different healthcare settings, increasing feasibility and optimizing long-term implementation. Furthermore, the inclusion of motivational strategies, such as follow-up phone calls and digital support tools, strengthens participant engagement and fosters sustained adherence, addressing a persistent challenge in chronic disease management.

Finally, the program places significant emphasis on the acquisition of practical skills, ensuring that knowledge is translatable into daily diabetes self-management behaviors. By prioritizing real-world applicability, the intervention aims to promote sustainable behavioral change, reinforcing its potential to generate long-term improvements in health outcomes for adults with diabetes and their families.

Conclusion

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This study contributes to the growing body of evidence supporting the integration of family-centered strategies in diabetes care, reinforcing the importance of addressing not only the individual's needs but also the family's role in disease management.

The intervention program demonstrates a promising approach to diabetes care, characterized by its evidence-based foundation, flexible design, and emphasis on family involvement. By integrating the family as a central component in diabetes management, the program not only enhances the quality of life for individuals with diabetes but also strengthens the capacity for sustained self-management. Empowering both the adult with diabetes and their family fosters shared responsibility and improves self-efficacy, leading to better health outcomes and a reduction in diabetes related complications.

To maximize its potential, future research should focus on refining the program, addressing identified limitations, and exploring its scalability in diverse healthcare settings.

Implications for practice

Integrating flexible, family-centered approaches in diabetes care can transform current practices by moving beyond an individual-focused model to one that treats the family as a key component of care. Tailoring interventions to family dynamics and specific needs can significantly enhance the sustainability of diabetes management outcomes. The "Juntos com a Família + Capazes" program serves as a model for other chronic disease interventions, demonstrating how family involvement can foster shared responsibility and long-term health improvements.

Future research should assess the program's long-term effectiveness by examining its impact on key variables, including health-related quality of life, diabetes-specific knowledge, self-efficacy in diabetes management, and family functioning. Additionally, evaluating its

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scalability and integration within existing healthcare systems will be crucial for facilitating broader implementation and ensuring the sustainability of its benefits across diverse settings.

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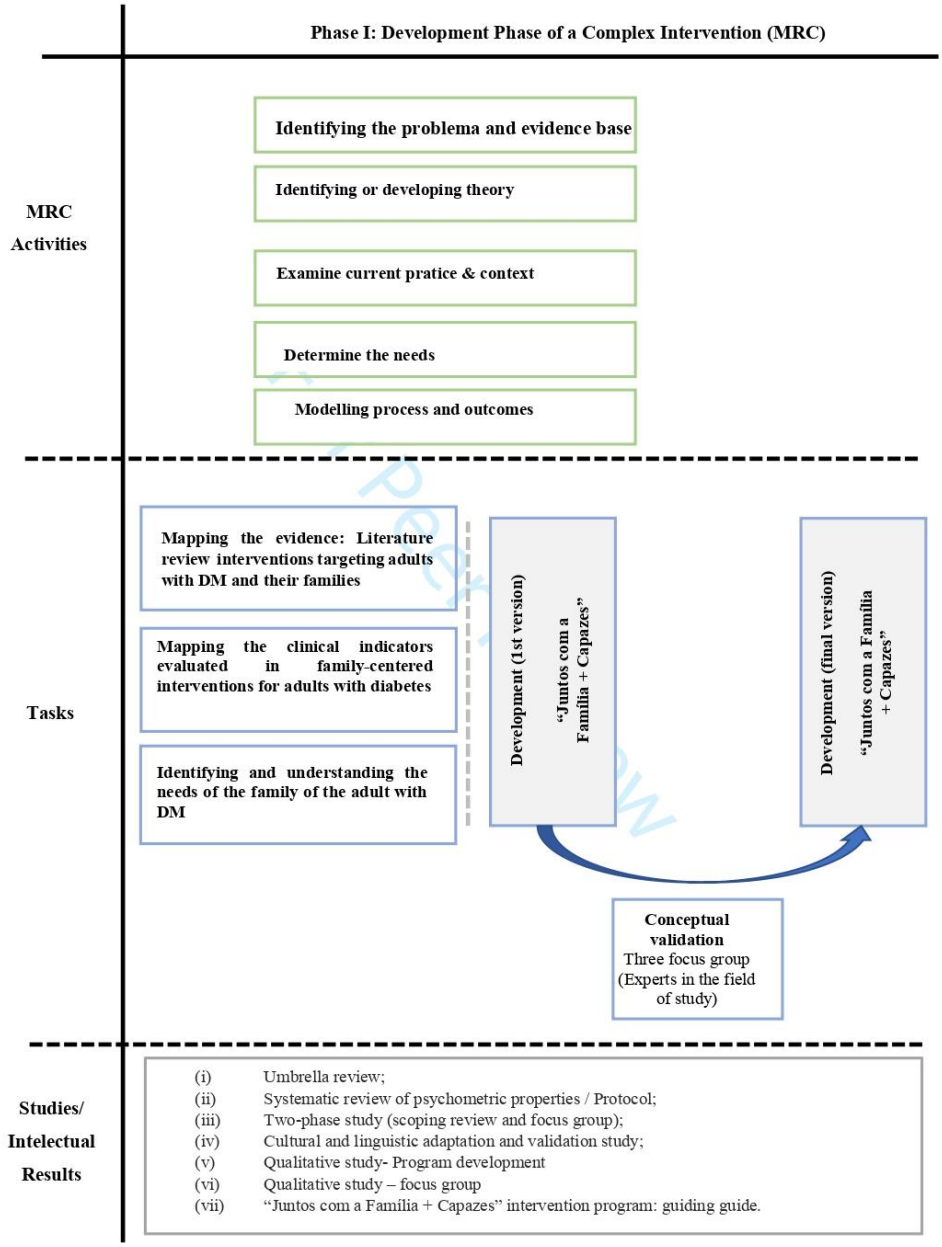

Figure 1. "Juntos com a Família + Capazes" Program Development

For Peer Review

Table 1. Intervention program *Juntos com a Família + Capazes*: Main elements

Juntos com a Família + Capazes					
Duration 6 months					
Session	Modules	Sessions	Duration	Participants	
1	Baseline	Ranged between 7 and 12 sessions	Between 60 and 120 minutes	Dyad Adult with diabetes and family member)	Maximum 10
Range between 5 and 10	- Transforming Habits - Balanced Nutrition - Movement and Health - Family and Communication - Diabetes Mellitus				
Closing session	Final				

For Peer Review

ARTIGO: "*Conceptual Validation of a Family-centered Diabetes Intervention: Insights from Multidisciplinary Focus Groups"* – **Artigo submetido para publicação na *BMC Primary Care***

Title: Conceptual Validation of a Family-Centered Diabetes Intervention: Insights from Multidisciplinary Focus Groups

Abstract

Background: Diabetes mellitus is a global health challenge requiring complex self-management strategies that extend beyond the individual to include family support. Family-centered interventions have been shown to enhance diabetes self-management, improve clinical and psychosocial outcomes, and promote adherence to therapeutic regimens. However, many existing interventions lack structured theoretical foundations and fail to integrate family engagement effectively. This study aims to conceptually validate the *Juntos com a Família + Capazes* intervention program, a psychoeducational, family-centered initiative designed to empower adults with diabetes and their families.

Methods: A qualitative descriptive study was conducted using focus groups to refine and validate the intervention program's structure, content, and methodologies. Focus groups were conducted healthcare and academic experts in chronic disease management, as well as with adults diagnosed with diabetes and their family members. Discussions were guided by a semi-structured interview protocol, recorded, transcribed, and analyzed using qualitative content analysis. The study adhered to the COREQ guidelines for qualitative research rigor.

Results: Three focus groups were held (n=19): two with multidisciplinary professionals and one with adults diagnosed with diabetes and their family. The *intervention* program was validated as a six-month intervention followed by a six-month follow-up period. It is structured into seven mandatory modules, with the number of sessions ranging from 7 to 12, depending on participant needs. The program incorporates various educational and behavioral strategies to support diabetes management. Experts highlighted the importance of flexibility in session duration and frequency, allowing facilitators to tailor the intervention

to each group. Active and participatory strategies were highlighted as the most effective for engagement, with experts also endorsing motivational and follow-up calls to sustain participation and reinforce self-management. The conceptual validation confirmed the necessity of these approaches to align the program with real-world healthcare settings.

Conclusions: The *intervention* program was validated as an evidence-based, adaptable, and family-centered intervention for diabetes management. The findings support the necessity of structured, theory-driven programs that actively engage families in diabetes care. Future research should focus on assessing the program's long-term impact on clinical and psychosocial outcomes, as well as its scalability across diverse healthcare settings.

Keywords: Focus group; Validation Study; Program development, family, diabetes, adults, qualitative research

Background

Diabetes mellitus (DM) is a global health emergency, affecting approximately 537 million adults [1]. Its increasing prevalence is driven by rapid social and cultural transitions, population aging, and urbanization-related behavioral changes [1]. Consequently, there is an urgent need for more effective strategies that not only address the growing epidemiological trends, but also reduce the significant economic burden associated with diabetes management and its complications [1, 2].

Effective diabetes management requires complex self-management activities that often take place within the family environment [3, 4]. These demands can be emotionally, physically, and socially challenging, affecting both the diagnosed person but also their family [5, 6]. Family involvement plays a bidirectional role in diabetes care, shaping and being shaped by the adult's experience with the disease [7]. Effective adaptation and disease management are

heavily influenced by family dynamics, making the role of family members crucial in facilitating acceptance and adherence to self-care practices [8].

As a result, family involvement is increasingly recognized as essential for diabetes management, with research and clinical guidelines emphasizing its role in promoting behavioral, educational, and psychological adaptations necessary for effective disease control necessary [9, 10]. Various strategies have been proposed to improve diabetes prevention and management [1, 11]. Among these, family-centered interventions have shown positive effects on clinical and psychosocial outcomes [12]. However, their implementation remains inconsistent, often lacking a structured theoretical framework and standardized methods for integrating family engagement [13].

Beyond increasing diabetes-specific knowledge, effective family-centered interventions should focus on empowering individuals and families, fostering autonomy in disease management, and promoting the rational use of healthcare resources [14]. Psychoeducational interventions, in particular, have shown potential in improving the quality of life for adults with diabetes and their families by adopting a holistic approach that considers social, economic, and behavioral factors alongside medical needs [11, 15, 16].

As intervenções psoeducativas tem vindo a ser destacadas na literatura como tendo potencial para melhorar a qualidade de vida da pessoa com diabetes e família, ao permitir uma abordagem holistica que vão de acordo com as individual characteristics and behaviors but also by broader social, physical and economic contexts, psychoeducational interventions have the potential to significantly improve the quality of life of people with diabetes [11, 15, 16].

Despite growing recognition of family-centered approaches, structured interventions that effectively incorporate family engagement remain limited, particularly for adults with

diabetes [13]. A more in-depth understanding of family dynamics, communication patterns, and support mechanisms is essential for developing tailored interventions that align with the actual needs of individuals with diabetes and their families [13].

To address these gaps, this study employed a qualitative research design using focus groups to validate the conceptual framework of a family-centered psychoeducational intervention, *Juntos com a Família + Capazes*. The study aimed to explore the perspectives of both healthcare professionals and adults with diabetes and their families regarding the structure, content, and feasibility of the intervention.

Method

This qualitative study employed a focus group approach to validate the conceptual framework of the intervention program *Juntos Com a Família + Capazes* (*Together with the Family + Capable*).

Focus group are widely recognized as an effective method for collecting qualitative data, allowing for in-depth discussions among participants within a socially interactive setting. This format facilitates the exploration of individual and shared perspectives on specific topics while fostering a dynamic exchange of experiences [17, 18]. To ensure a diverse range of insights while maintaining an environment conducive to open discussion, each focus group was limited to a maximum of 10 participants. This number was chosen to balance information richness while ensuring that participants felt comfortable expressing their thoughts, opinions, and experiences. Each session lasted a maximum of two hours

Data collection

Focus group discussions were conducted to explore participants' knowledge and experiences regarding the structure, content, and methodology of the *Juntos com a Família + Capazes* intervention program. The research team developed a structured interview guide to facilitate

discussions and maintain consistency across sessions. Each focus group session began with a brief introduction by the moderator, followed by an explanation of the study's objectives and the distribution of participant information sheets and consent forms, which were signed before discussions commenced.

A digital audio recorder was used to capture discussions, with explicit prior consent from participants. These recordings were used solely to aid transcription. The sessions were moderated by the lead author, a PhD candidate in Nursing Science with extensive experience in both clinical practice and qualitative research. The moderator adhered to focus group facilitation principles, ensuring that discussions remained aligned with study objectives and avoiding personal biases. An observer, also a PhD candidate with expertise in qualitative research, took field notes to supplement the audio recordings [19].

Focus groups were conducted between January and May 2024. Based on participant preferences, the first two sessions were held online via Zoom, while the third was conducted in person at a healthcare facility in Alto Minho. Data saturation was achieved when no new themes emerged across discussions.

Participants

To allow for a more comprehensive approach that integrates different perspectives, the participants included not only professionals, but also those who experience the management of diabetes and its consequences, diagnosed adults and their families

Multidisciplinary experts' inclusion criteria:

Multidisciplinary professionals were recruited through personal contacts, email, and telephone outreach by the research team. The inclusion criteria included : (i) Experience working with individuals diagnosed with diabetes or other chronic illnesses and their families; (ii) Experience in either clinical practice or research, particularly in developing and

evaluating intervention programs for these populations. All professionals were provided with detailed information about the study's objectives, their expected role, and the focus group procedures.

Adults diagnosed with diabetes and their family's inclusion criteria

Adults with diabetes and their family members were recruited through healthcare professionals from the Family Health Unit, who initially contacted potential participants by phone to assess their interest. The researcher then conducted a screening process to ensure all participants met the inclusion criteria. Efforts were made to achieve a diverse sample, considering age, gender, and socioeconomic background.

The inclusion criteria for adults with diabetes required them to be 18 years or older. For family members, the criteria included: (i) Being at least 18 years old; (ii) Having an active role in supporting diabetes management.

The definition of "family" followed the conceptualization proposed by Wright and Leahey (2013), which recognizes family as *"who its members say they are."* Individuals with cognitive impairments were excluded from participation.

Ethical Considerations

Ethical approval for this study was granted by the Ethics Committee of Alto Minho Local Health (Decree-Law No. 97/95 of 10 May, revised by Decree-Law No. 80/2018 of 15 October). Participants received comprehensive information about the study's purpose, methods, and potential benefits. Confidentiality and anonymity were strictly maintained, and participants was entirely voluntary, with the option to withdraw at any time without consequences. Written informed consent was obtained from all participants before the focus group sessions.

Data Analysis

Data were analyzed using Mayring's Qualitative Content Analysis (QCA), a structured method that allows for a systematic and detailed examination of textual data [20]. This approach ensured that the analysis remained coherent and accurately reflected participant perspectives while preserving the original meaning of their statements. This method guarantees the reliability and validity of the analysis.

Validity and reliability

To ensure the validity and reliability of the data collected in the focus groups, this study followed the guidelines of the COREQ (Consolidated Criteria for Reporting Qualitative Research) checklist. Measures taken to guarantee the transferability of the results, and the validity and reliability of the study included: (i) Participant diversity: a purposive sampling strategy ensured a diverse representation in terms of age, gender, socioeconomic status, and educational background; (ii) **Moderator and observer roles:** An experienced moderator facilitated discussions while an observer took field notes to ensure comprehensive data capture; (iii) **Audio recording and transcription:** All focus group discussions were audio-recorded (with prior consent) and fully transcribed for accurate analysis. Preliminarily analyzed data were shared with participants to verify accuracy and interpretations; (iv) Inter-coder reliability: Two independent researchers coded the transcripts separately, resolving discrepancies through discussion to ensure consistency and objectivity.

Excerpts from participants' statements were incorporated into the results to illustrate key findings. To ensure clarity, multidisciplinary professionals are identified by the initials "EP," while adults with diabetes and their family members are denoted as "EDF." Each statement is labeled with a unique identification number (e.g., “EP1”).

Results

All the participants (n= 19) accepted the invitation to take part in the study, and none withdrew. Three focus groups were conducted, lasting a maximum of 90 minutes, to assess the intervention program's structure, content, and proposed methodologies. After the third session, the research team concluded that no new themes had emerged, indicating that data saturation had been reached.

Two of three focus group included multidisciplinary professionals, while the third consisted of adults with diabetes and their family members. Initially, the research team intended to hold mixed groups, combining professionals with adults with diabetes and their families. However, none of the adults with diabetes or their families agreeded to participate via Zoom due to either a lack of necessary digital devices or limited digital literacy. Conversely, the healthcare professionals, given their demanding schedules and geographical dispersion across the country, were unavailable for in-person meetings. As a result, the research team decided to conduct the focus groups with professionals online via Zoom, while the session with adults with diabetes and their families was held in person.

Participants Characteristics

(i) Multidisciplinary Experts: The majority were female, with an average age of 48.7 years (range between 29 and 68 years). Participants held diverse professionals' roles, including primary care physician, general nurse, family nurse, associated professor, full professor, principal adjunct professor, researcher, coordinator nurse, coordinator professor. Regarding their expertise, 22% specialized exclusively in diabetes, 22% focused on chronic disease, and 56% had experience in both diabetes and chronic disease management. In terms of career duration, 67% had over 20 years of experience in diabetes and/or chronic disease

management, research, or training, 22% had between 11 and 20 years, and 11% had less than 10 years of experience. All participants had research experience, and 89% reported both research and management experience in diabetes and/or chronic disease;

(ii) Adults with Diabetes: Predominantly male, with an average age of 71.6 years (range: 58-83 years). The duration since diagnosis ranged from 2 to 18 years, with an average of 7.8 years;

(iii) Family Members: Primarily female, aged between 54 and 78 years, with an average age of 67.4 years. Their involvement in diabetes management ranged from two to 18 years, with an average duration of 7.8 years. All participants lived with the individual diagnosed with diabetes;

Further methodological details are provided in the COREQ Checklist details (Supplementary material, File 1).

The participants were asked about four main themes about the intervention program, which included: Structure; Content; Strategies; Expected outcomes.

Program Structure

This theme encompassed the following categories: participant recruitment and inclusion criteria; target population for the sessions; session duration; duration of the program and follow up; total number of sessions; interval between sessions.

Participant's recruitment and inclusion criteria: All experts agreed that participants recruitment should be conducted by professionals from the multidisciplinary team, from different levels of care, or through people self-referral, provided that individuals met the predefined inclusion criteria. These criteria, which were unanimously accepted by all experts, required that adults with diabetes be aged 18 years or older, regularly attend

healthcare appointments, possess the ability to speak, read, and understand Portuguese, and have no cognitive impairment that would hinder their participation in the intervention. Family member were also required to be aged 18 years or older, speak, read, and understand Portuguese, and have no cognitive impairment that limits their participation in the intervention. The definition of family was not restricted to biological relationships but was instead aligned with the Calgary Theoretical Models, recognizing family as defined by the individual with diabetes [8]. Pregnant women with diabetes will be excluded from participation.

Target population: When asked about the target population for each session, all experts agreed that it should consist of the dyad, composed of the adult with diabetes and their family member. They emphasized that participation as a dyad fosters a more supportive family environment and prevents situations where one individual feel that important information is being withheld from them.

> "…it doesn't make sense to separate the family and the people diagnosed... it could cause some mistrust between them..." EP6

> "…I like things to be explained to me at the same time as they're explained to my wife, because she doesn't ask questions, but I do and so I help her…" EDF6

Session duration: Regarding this topic, opinions varied on the optimal length of the sessions, and no consensus was reached. While about half of experts considered 120 minutes to be too long and suggested that 90 minutes would be sufficient, the remaining experts believed that 90 minutes was insufficient to adequately cover the necessary content and allow for meaningful participation.

> " ... my only concern is the length of each session... 120 minutes would be too long..." EP8

> "... I also agree that it's exaggerated... in my opinion and from my experience in psychoeducational groups, I think it's a lot in a group what's standardized is 90 minutes (...) but I also think it depends a lot on the dynamism of the session and the tasks we're going to develop in the sessions. But for me, the ideal would be 90 minutes" EP5

> "...from my experience...I've done a few psycho-educational groups similar to this one and I think that sometimes the 90 minutes wasn't enough...my point is that it depends a lot on the sessions and the type of session we're doing. Maybe there could be a variation between the sessions, that is, depending on the session we were doing, we could vary between 90 and 120 minutes (...) I think we could adjust (the duration of the sessions) according to the objectives of each session (...) because there are sessions that have many objectives (...) many tasks involved in those objectives for the sessions (...) maybe some (sessions) could be 120 minutes and others 90 minutes (...)" EP7

> "…the length of the sessions will depend on our doubts, won't it... sometimes there are subjects that are difficult to understand straight away..." EDF 4

One of the experts suggested that session duration should range between 90 and 120 minutes. This recommendation was unanimously accepted, leading to the decision that the program facilitator would have the flexibility to adjust the duration of each session based on the specific characteristics of the intervention group and the objectives of each session.

Duration of the program and follow up: Regarding the duration of the program, all experts agreed that the six-month intervention period proposed by the research team was the most appropriate. Additionally, an equivalent six-month follow-up period was proposed and validated by the experts.

"…yes, it seems to me that six months is an adequate time..." EP5

" … from my experience is the right time..." EP7

Additionally, the researchers proposed to the experts, who fully endorsed the suggestion, that six monthly motivational phone calls, each lasting a maximum of 15 minutes, be conducted during the implementation phase of the intervention program. Likewise, during the follow-up period, six additional monthly phone calls, with a maximum duration of 20 minutes each, would be carried out to maintain participant engagement and support long-term adherence.

"…Yes, I agree… it seems appropriate..." EF4

"…I agree ... with making the calls and with its duration" EF6

"…Yes... more time doesn't seem to make sense to me…"EP5

Total number of sessions: With regard to the number of sessions, all experts agreed with the proposed seven-session structure (one per module). However, one expert, drawing from extensive experience in the field and in program implementation, suggested that the number of sessions should be flexible and determined by the facilitators in collaboration with the group. This recommendation was unanimously considered appropriate and was subsequently incorporated into the program. Thus, it was determined that the number of sessions should range from a minimum of seven to a maximum of twelve.

"... so I don't know if I should leave this number open and give it almost as a recommendation. The program has to have at least 7 sessions and can go up to 12 sessions..." EP7

" … Yes, it seems to me that this flexibility makes sense... because the success of the program will be greater the more it can meet the needs of the participants…"EP6

Interval between sessions: Regarding the interval between sessions, there was unanimous agreement among experts that, due to time constraints and to minimize travel requirements, sessions should be spaced apart. A biweekly schedule (every 15 days) was proposed and unanimously accepted. However, one expert emphasized the importance of scheduling all sessions during the baseline session (session zero) to allow participants to plan their personal commitments accordingly and maintain their routines throughout the intervention.

> "…Yes, twice a month seems reasonable, as in-person sessions require travel …and it is not always easy to align sessions with participants' daily schedules…" EP5

> "…Yes, this works well because it allows us to manage our responsibilities without constantly worrying about the meetings… "EDF9

Another aspect that was highlighted by the experts was the importance of the sessions being scheduled in their entirety at "session zero"

> "(...) we have to know our life... we have to organize ourselves to be able to attend all the sessions (...)" EDF3

Program Content

This theme encompassed the following categories: the content of the modules to be covered and the sequence in which these contents will be addressed.

Content of the modules: All experts approved the proposed content; however, several suggestions were made regarding the sequencing of topics and the titles of the modules.

It was therefore suggested that the content should focus more on practical strategies that participants could replicate in their daily lives, rather than on theoretical exposition. It was suggested by all the experts that the focus of the program should be on empowering participants to effectively manage their diabetes and prevent possible complications,

according to the specificities of the participants and the socio-economic context in which they live.

> "...the program to make a difference and what the literature shows is that the more tailored the programs are to people's specific needs, the more successful they are, of course (...) so I think it's a bit like that (...) it's not saying diabetes is this problem, you can have this type, you can have that, people don't want to know about it (...)" EP5

The title of the module on complications should therefore be possible associated complications and not just complications.

> "...the logic that this program should have been (...) to prevent complications, or rather, possible complications, because possible gives us the chance of not having them. Then what impact would people have, who don't realize it because they know that diabetes doesn't hurt, at least most of the time, what are the possible complications? (...) What possible impact (...) on people's lives? And, by the way, on the family's life, these complications that could possibly be avoided in most cases (...)" EP4

The suggestions were included in the program and the content was structured into seven compulsory modules, the first being "Module Zero: Baseline" and the last being "Final Module: Closing Session". The five modules that make up the program, although compulsory, should be approached in the order established between the facilitator and the participants, according to the felt and expressed needs of the participants. The contents of each module are described in Table 1.

Table 1. Overview of the "Juntos com a Família + Capazes" Intervention Program Content

"JUNTOS COM A FAMÍLIA + CAPAZES" MODULES	**PARTICIPANTS**

Module Baseline	Dyad: adults with diabetes and their families
Transforming Habits: Pathways to a Healthy Lifestyle in Diabetes Management	
Balanced Nutrition: A Healthy Approach to Diabetes Management	
Movement and Health: The Importance of Physical Activity in Diabetes Management	
Family and Communication: Essential Family Dynamics in Managing Diabetes Mellitus	
Diabetes Mellitus: Understanding, Self-Monitoring, and Overcoming Possible Complications for a Full Life	
Module Final Session	

Program Strategies

All the strategies proposed in the intervention program were considered appropriate by all experts. However, the most participatory strategies that actively engaged participants were particularly highlighted.

Regarding strategies that included digital platforms as an alternative to in-person sessions, as well as the creation of private social media pages and a WhatsApp group for participant interactions, these aspects prompted deeper discussion among the experts. They reported that, based on their professional practice and previous experiences, the adoption of these strategies was not always successful, as some participants lacked the necessary resources or digital literacy to engage with online platforms and social networks effectively.

These findings were corroborated by the expert group composed of adults diagnosed with diabetes and their family members. One participant stated:

> *"(...) my wife and I struggle with computers and more modern mobile phones (...)"*
>
> *EDF 6*

This sentiment that was unanimously shared by the other participants, who expressed a clear preference for in-person sessions.

Consequently, it was decided that the use of new technologies for content sharing and reinforcement should be proposed in Session Zero (Baseline) and only implemented if all participants possessed the necessary digital skills and access to appropriate equipment. Additionally, experts suggested that if digital strategies were feasible and appropriate, a blog should be created to compile and share all relevant information covered in each module.

Outcomes expected to change

The theme "Expected Outcomes" encompassed the key areas in which the research team anticipates improvements following the implementation of the intervention program. These outcomes were identified based on the theoretical foundations of the program and expert contributions, ensuring alignment with the intervention's objectives and the expected impact on participants.

Expected health outcomes include improvements in key clinical indicators relevant to diabetes management, such as Body Mass Index (BMI), glycated hemoglobin (HbA1c), waist circumference, blood pressure (systolic and diastolic), alcohol consumption (measured in drinks per day), and smoking habits (measured in cigarettes per day).

> "…I think so... that they are enough..." EP8

> "… in my experience with these programs for people with diabetes, I believe the main outcomes are indeed these, particularly in the context of diabetes management…" EP9

Additionally, the program is designed to improve self-management behaviors, including adherence to prescribed treatment regimens, medication compliance, and the consistent

monitoring of blood glucose levels. Increased engagement in health-promoting behaviors, such as regular physical activity (measure in hours per week) and balanced nutrition, is expected to contribute to better metabolic control and overall well-being.

> "…those are the health gains expected from a program of this nature…" EP4

By fostering family involvement in diabetes management, the intervention program is expected to cultivate a sense of shared responsibility, alleviating the psychological burden often experienced by both the diagnosed individual and their family members. This, in turn, is anticipated to lead to improvements in health-related quality of life, enhanced self-efficacy in diabetes management, and strengthened overall family functioning.

Moreover, improvements in health literacy are a key objective, as higher levels of diabetes-specific knowledge are associated with better self-care behaviors, improved navigation of healthcare resources, and increased capacity to make informed health decisions.

> "…For me, these are fundamental aspects to assess because we know that diabetes has a strong positive association with stress and depressive symptoms…" EP6

Discussion

The *Juntos com a Família + Capazes* intervention program addresses a critical gap in adult diabetes management by adopting a family-centered approach that extends beyond traditional patient-focused education. By promoting family involvement in diabetes care, this intervention aligns with international recommendations and recent studies highlighting the family's role as a key determinant of intervention success, improved patient outcomes, and sustained self-management behaviors [2, 21].

The conceptual validation of the intervention program through focus group provided an efficient and cost-effective method for gathering insights from multiple stakeholders, enabling an iterative refinement of the intervention [17] . This process, which engaged

multidisciplinary experts alongside adults with diabetes and their families, was instrumental in ensuring that the intervention aligns with both clinical practice and the lived experiences of those managing diabetes. The inclusion of diverse perspectives enriched the intervention's content, contributing to its effectiveness by actively involving patients and their families in a co-constructed healthcare approach [17, 22].

By engaging experts—including those directly affected by the disease—the intervention fosters a sense of ownership among participants, creating a safe space for discussion, spontaneous contributions, and shared problem-solving [17]. This approach not only integrates insights from healthcare professionals but also incorporates the lived experiences of individuals managing diabetes daily, addressing their challenges, needs, and the psychosocial and emotional aspects that influence health outcomes, including the broader social determinants that shape health behaviors [25].

The validation process, of an intervention program based on the MRC Framework for Complex Interventions and the Calgary Family Assessment and Intervention Model (CFAIM), ensures that the intervention is not only evidence-based and methodologically rigorous, but also adaptable to the specific needs of each dyad and their contextual realities [8, 23].

The focus group experts unanimously emphasized the importance of actively involving family members in program sessions—not only to reinforce diabetes self-management behaviors but also to enhance the well-being of both the diagnosed individual and their supporting family members [10].

Across the various components of the intervention, experts agreed that while the program should follow structured guidelines, it must remain flexible and adaptable to the target

population and implementation context. These findings align with the literature, which emphasizes the importance of culturally and contextually relevant interventions [11,15].

The intervention program is structured yet adaptable, incorporating strategies that engage families in diabetes management while addressing both the educational needs of individuals and the relational dynamics within the family unit [24]. By integrating both practical diabetes management skills and the socio-economic and cultural realities of participants, the program ensures a holistic and personalized approach.

Through this conceptual validation process, the intervention aims to enhance its effectiveness in improving both clinical and psychosocial outcomes that are critical in diabetes care [25]. Strengthening family functioning is expected to foster a supportive environment that enhances the individual's self-management capacity, facilitates adherence to treatment, and encourages sustained healthy lifestyle behaviors, ultimately contributing to long-term health improvements [26].

A key component of the program's strategies is the definition and achievement of Specific, Measurable, Achievable, Relevant, and Time-Bound (SMART) objectives during motivational and follow-up calls with the diagnosed adult [27]. This approach ensures that goals are clearly defined and actionable, promoting continuous progress in diabetes management and empowering participants to take an active role in their health [27].

Expert feedback played a crucial role in refining the program's strategies by emphasizing the importance of incorporating practical diabetes management approaches rooted in everyday experiences and family relationships. This adjustment increases the likelihood that the intervention will effectively address the diverse needs of individuals and families coping with diabetes. A particularly significant moment in the focus group discussions was the recommendation to modify the title of the module addressing diabetes management and

complications, adding the term “potential complications.” This modification was suggested to reinforce the idea that complications are not inevitable but rather a consequence of insufficient support, underscoring the shared responsibility of healthcare professionals, individuals with diabetes, and their families in preventing complications through effective diabetes management [11, 28, 29].

To improve diabetes care and develop effective interventions, healthcare professionals must consider these determinants while also incorporating the perspectives of individuals with diabetes and their families, who are experts in their own health journeys [11,15].

The use of digital tools during the focus groups revealed significant challenges related to digital literacy and access. The low digital literacy levels among diagnosed adults and their families were consistent with findings in the literature, which highlight these issues as particularly concerning among older adults [16, 30]. This finding reinforced the need for flexible strategies in the intervention. While digital tools can enhance engagement, they may also present barriers to participation. To address this, the program incorporates alternative face-to-face sessions or telephone-based support, ensuring that technological limitations do not exclude participants. This adaptability not only mitigates the impact of digital disparities but also enhances inclusivity, making the intervention accessible regardless of participants' technological skills or access to digital resources [30].

By addressing these digital access challenges and considering the specific needs and contexts of participants through a holistic assessment, the program demonstrates a commitment to equitable healthcare delivery [31, 32]. It ensures that all participants, regardless of their technological capabilities, can fully benefit from the intervention. This flexibility is essential in reducing inequalities in health education and care, particularly in chronic disease management, where sustained engagement and support are critical.

Future adaptations of the program should continue to prioritize accessibility, integrating both digital and non-digital options to maximize reach and effectiveness across diverse populations.

Conclusion

The *Juntos com a Família + Capazes* intervention program represents a significant step toward integrating family-centered approaches into diabetes management. By incorporating insights from multidisciplinary experts, adults with diabetes, and their families, the conceptual validation process ensured that the program is both evidence-based and adaptable to the real-world needs of participants. The emphasis on structured yet flexible strategies, including the active involvement of family members, aligns with international recommendations and emerging research highlighting the critical role of family support in improving diabetes self-management and overall well-being.

The discussions held during the focus groups underscored the importance of tailoring the intervention to the socio-cultural contexts and individual needs of participants. Expert feedback reinforced the necessity of practical and participatory methodologies, which enhance engagement and long-term adherence to diabetes self-management practices. Moreover, the insights gained on digital literacy barriers highlighted the importance of offering multiple engagement formats to ensure accessibility for all participants.

This research contributes to the growing body of evidence supporting family-centered care models and reinforces the necessity of structured, theory-based interventions that promote sustainable diabetes self-management and improve patient and family well-being. By shifting from a traditional patient-centered model to a family-inclusive approach, the program not only empowers individuals with diabetes but also strengthens the support

systems essential for long-term disease management. Future adaptations should continue to prioritize accessibility and personalization, ensuring that the intervention remains relevant and effective across diverse healthcare settings.

Declarations

Ethics approval and consent to participate

All participants provided written informed consent before the focus group discussions, and ethics approval was obtained from the Ethics Committee of Alto Minho Local Health (Decree-Law No 97/95 of 10 May, revised by Decree-Law No 80/2018 of 15 October).

Consent for publication

Not applicable

Availability of data and materials

The datasets used and/or analyzed during the current study are available from the corresponding author on reasonable request.

Competing interests

The authors report no competing interests

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Authors' contributions

VLS: Conceptualization, Methodology, Investigation, Data curation, Writing- Original draft preparation; MCBF: Conceptualization, Supervision, Writing- Reviewing and Editing; MCM: Conceptualization, Supervision; CS: Conceptualization, Supervision.

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PROGRAMA INTERVENÇÃO: *Juntos com a Família + Capazes*: Guia Orientador para Profissionais

PROGRAMA DE INTERVENÇÃO *JUNTOS COM A FAMÍLIA + CAPAZES*

GUIA ORIENTADOR

Programa de intervenção psicoeducativo de Enfermagem *Juntos com a família + Capazes*

Investigador: Vânia Lídia Silva Soares

Orientadores:

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Descrição da investigação: A Diabetes Mellitus (DM) é uma condição responsável por um número elevado de mortes prematuras e incapacidades (IDF, 2021). Considerada uma emergência global de saúde pública, a diabetes desafia diariamente os sistemas de saúde e os decisores clínicos a desenvolver estratégias mais efetivas, que permitam reduzir as curvas epidemiológicas da doença, os custos associados ao seu tratamento e as complicações que lhe estão associadas.

A gestão da diabetes exige cuidados contínuos e complexos, que frequentemente representam desafios significativos para a adesão e manutenção por parte das pessoas diagnosticadas (American Diabetes Association, 2023). Esta dificuldade deve-se, em grande parte, à complexidade dos regimes terapêuticos e à perceção das pessoas diagnosticadas de que os cuidados de saúde não respondem de forma adequada às suas necessidades reais (International Diabetes Federation, 2021).

A revisão da literatura evidencia uma diversidade de intervenções desenvolvidas na área da diabetes, salientando, contudo, a necessidade de uma abordagem personalizada que considere as especificidades individuais e dos contextos e da sua família. Para além de assegurar cuidados baseados na melhor evidência científica, torna-se essencial que estes sejam ajustados às necessidades, objetivos e preferências dos doentes e dos seus familiares, promovendo um modelo de cuidados centrado na pessoa e na família.

O programa de intervenção *Juntos com a Família + Capazes* foi desenvolvido com base na evidência científica mais recente sobre a diabetes no adulto e no papel da família na gestão

da doença, integrando recomendações internacionais e diretrizes publicadas por diversas entidades de referência na área (American Diabetes Association, 2023; International Diabetes Federation, 2021; Observatório Nacional da Diabetes, 2019). A sua validação conceptual, abrangendo estrutura, conteúdos e metodologia, foi realizada através de três grupos focais, com peritos de diversas áreas, bem como de pessoas diagnosticadas e seus familiares.

O programa foi desenvolvido tendo por base os Modelos de Avaliação e Intervenção Familiar de *Calgary* (CFAM e CFIM) e o Modelo de Intervenções Complexas do *Medical Research Council* (MRC). Os Modelos de Calgary fornecem um enquadramento estruturado para a prática de enfermagem com a família, permitindo estruturar a avaliação, o diagnóstico e a implementação do programa com foco em todas as dimensões do funcionamento familiar (Wright & Leahey, 2013). Adicionalmente, o modelo MRC orientou o desenvolvimento do programa enquanto intervenção complexa, assegurando a integração de abordagens sistemáticas e flexíveis, ajustadas às necessidades específicas do adulto com diabetes e da sua família (Bleijenberg et al., 2018; Craig et al., 2008; Richards & Hallberg, 2015). Esta combinação teórica possibilitou o alinhamento dos conteúdos e estratégias do programa às melhores práticas baseadas na evidência científica e na experiência clínica, promovendo uma gestão holística e efetiva da doença (Bleijenberg et al., 2018; Craig et al., 2008; Richards & Hallberg, 2015).

CUIDAR DE FORMA PERSONALIZADA O ADULTO COM DIABETES E FAMÍLIA

O cuidado personalizado do adulto com diabetes e sua família deve ser iniciado desde o momento do diagnóstico e deve atender às suas especificidades e necessidades na gestão da doença, considerando o impacto que esta tem na dinâmica familiar. O enfermeiro, detentor de um conhecimento aprofundado sobre o processo saúde-doença, sobre as pessoas e os seus contextos, assume um papel central no suporte e monitorização contínuos da pessoa diagnosticada e da sua família. Para garantir a efetividade deste acompanhamento, é essencial que esse cuidado seja estruturado com base num processo de enfermagem holístico e sistemático, centrado na família, promovendo a adaptação e capacitação da díade para uma gestão autónoma e sustentável da doença (Wright & Leahey, 2013).

Com base numa avaliação abrangente, o enfermeiro identifica diagnósticos de enfermagem que podem abranger desde questões de saúde específicas até necessidades de apoio

emocional, dificuldades de comunicação e desafios nas dinâmicas familiares. O planeamento das intervenções deve estar ancorado nas necessidades individuais da pessoa com diabetes e da sua família, considerando os fatores contextuais que influenciam a saúde e que podem facilitar ou dificultar a autogestão da doença.

Adicionalmente, a avaliação deve integrar informações relevantes provenientes de diferentes níveis de cuidados e da equipa multidisciplinar, promovendo uma articulação efetiva entre os profissionais, garantindo um acompanhamento mais holístico e coordenado (Ferreira et al., 2024). Com esse conhecimento aprofundado, o enfermeiro, em parceria com a pessoa diagnosticada e a sua a família, desenvolve um plano de cuidados personalizado.

Durante a elaboração deste plano, são definidas, em colaboração com a pessoa diagnosticada e a família, intervenções específicas e objetivos claros. Este processo de cocriação fortalece o papel da família como um recurso essencial no suporte à gestão da diabetes, facilitando a adesão ao regime terapêutico e reduzindo o risco de complicações futuras. A continuidade do apoio por parte da equipa multidisciplinar e a integração de recursos comunitários são elementos essenciais para garantir um ambiente de suporte mais estável e sustentável, promovendo o empoderamento da díade e contribuindo para uma gestão mais eficaz e autónoma da diabetes.

O empoderamento efetivo da pessoa com diabetes e da sua família requer uma abordagem colaborativa e partilhada, centrada nas necessidades e objetivos de saúde definidos conjuntamente. Neste contexto, o programa Juntos com a *Família + Capazes* procura aumentar a literacia em saúde e a capacidade de autogestão da diabetes, promovendo uma parceria ativa entre os profissionais de saúde e a família. Esta abordagem assegura que o plano de cuidados personalizado seja implementado de forma participativa, assegurando uma tomada de decisão partilhada e alinhada com as expectativas e necessidades dos envolvidos.

O plano individual de cuidados para a gestão da DM deve ter como principal objetivo o empoderamento da pessoa com diabetes e da família, através do aumento da sua literacia em saúde, designadamente ao nível da autogestão da DM. Espera-se que este processo se traduza numa melhoria da qualidade de vida da pessoa diagnosticada e da sua família, e numa maior adesão ao regime terapêutico e na prevenção das possíveis complicações associadas à diabetes. Além disso, o plano deve incluir o mapeamento de recursos de apoio existentes na

comunidade e noutros contextos relevantes, fomentando uma rede de suporte que contribua para uma gestão da mais efetiva da diabetes e das relações familiares.

Programas de intervenção psicoeducativa, como o *Juntos com a Família + Capazes*, são amplamente recomendados por abordarem necessidades específicas identificadas desde o momento do diagnóstico. Ao permitir uma abordagem estruturada e direcionada, estes programas seguem as etapas do processo de intervenção em enfermagem — diagnóstico, planeamento, intervenção e avaliação —garantindo uma avaliação contínua. Dessa forma, asseguram que as intervenções permaneçam relevantes e ajustadas às necessidades em constante evolução da pessoa com DM e da sua família (Figura 1). A participação da díade — pessoa com DM e da sua família — numa intervenção psicoeducativa não só amplia o conhecimento sobre a doença e a sua gestão, como também promove uma parceria entre profissionais e participantes, fortalecendo a autonomia da pessoa e da família para lidar com os desafios da diabetes.

O empoderamento inicia-se com a negociação do plano de cuidados entre o enfermeiro, a pessoa diagnosticada e a família, garantindo um alinhamento entre as estratégias e as reais necessidades. Este processo fortalece a capacidade de autogestão da DM e favorece o acesso a informações de qualidade que irão contribuir para a concretização do seu potencial de saúde e para o exercício da cidadania em saúde (Ministério da Saúde, 2022).

Este alinhamento entre profissionais de saúde, pessoa diagnosticada e família reforça a importância de uma abordagem estruturada e personalizada, na qual a avaliação das especificidades familiares desempenha um papel central. Neste contexto, o Modelo de Avaliação Familiar de Calgary (CFAM) surge como um referencial essencial para compreender as dinâmicas familiares e orientar intervenções mais eficazes.

Avaliação das especificidades da família de acordo com o CFAM

A avaliação da pessoa diagnosticada e da família é uma etapa crítica do processo de enfermagem, devendo ser realizada de forma sistemática e abrangente, considerando todos os fatores que possam influenciar a saúde dos envolvidos (Wright & Leahey, 2013). De acordo com o Modelo de Avaliação de *Calgary*, esta avaliação deverá incluir três domínios essenciais — estrutural, de desenvolvimento e funcional — permitindo que profissionais e investigadores identifiquem e compreendam a dinâmica familiar única de cada família, as fases do seu desenvolvimento e as funções desempenhadas dentro do núcleo familiar, assim como os fatores que influenciam a saúde da família Este modelo organiza as etapas de

avaliação, diagnóstico, planeamento, implementação e reavaliação das intervenções, assegurando uma abordagem abrangente que considera todas as dimensões do funcionamento familiar (Wright & Leahey, 2013).

Os Modelos de Avaliação e Intervenção Familiar de *Calgary* proporcionam uma base científica para estratégias adaptadas às necessidades das famílias, promovendo um cuidado holístico e efetivo (Wright & Leahey, 2013). Estes modelos amplia a perspetiva dos profissionais de saúde, orientando-os para um "pensar a família", incentivando uma abordagem centrada na família, valorizando as dinâmicas familiares e o seu papel na promoção da saúde e do bem-estar.

O Modelo de Avaliação Familiar de *Calgary* (CFAM) propõe uma avaliação estruturada por domínios e suas subcategorias, os quais se descrevem de forma sucinta:

1. **Domínio Estrutural**: permite aos profissionais de saúde uma avaliação e compreensão da família de uma forma mais abrangente. Compreende informação pertinente sobre a composição da família com um adulto com DM e as influências externas que tem impacto nos membros da família e na gestão da doença. Neste domínio inclui-se também o impacto do contexto mais amplo, no qual a família se encontra inserida. Este pode incluir fatores como o acesso a serviços de saúde, redes de apoio social ou condições socioeconómicas. A avaliação deste domínio é fundamental para o desenvolvimento de intervenções personalizadas e alinhadas com as especificidades e necessidades da família e do adulto com DM.

   Este domínio inclui as seguintes subcategorias:

   - Estrutura interna: avalia a composição da família, o número de membros, as idades e as relações estabelecidas com o adulto diagnosticado com diabetes. Permite aos profissionais compreender as dinâmicas de género e a forma como estas podem influenciar a gestão da DM. Possibilita também a identificação de unidades menores dentro da família (como subsistemas conjugais, parentais e fraternos), bem como a avaliação da clareza e permeabilidade dos limites dentro da família e entre os seus subsistemas. Esta análise é crucial para entender como cada subsistema interage e contribui para o apoio ao adulto com diabetes, identificando potenciais barreiras ou facilitadores na gestão da doença.
   - Estrutura externa: nesta subcategoria, o profissional pode avaliar a existência de familiares estendidos que possam influenciar ou ser fonte de suporte ao adulto diagnosticado e aos demais membros da família. Inclui a identificação de sistemas

mais amplos, como o setor de saúde, educação, serviços sociais, emprego e instituições religiosas que interagem com a família e que de alguma forma influenciam a gestão da DM.

- Contexto: esta avaliação incide na compreensão dos padrões culturais relacionados com a etnia e nas implicações raciais que possam influenciar a motivação pessoal e a adesão do adulto diagnosticado a um estilo de vida saudável, bem como a comportamentos de saúde potenciadores de uma melhor gestão da Diabetes. Inclui-se de igual forma a avaliação do impacto das crenças e práticas religiosas da família na adesão aos regimes terapêuticos necessários para a gestão da doença. A análise da classe social da família, designadamente a sua condição socioeconómica, rendimentos e ocupação, assume-se como essencial pela sua influência na capacidade de a pessoa diagnosticada gerir a diabetes, refletida na capacidade de compra de alimentos mais saudáveis e medicação prescrita.

  Nesta subcategoria, consideram-se ainda o ambiente físico e social em que a família vive, designadamente os recursos comunitários. De forma mais específica, os profissionais podem avaliar a existência de parceiros na comunidade que possam promover a adesão dos participantes às intervenções, por exemplo através da cedência transporte ou de espaços comunitários de maior proximidade à população e de fácil acesso.

2. **Domínio de Desenvolvimento:** permite aos profissionais compreender a evolução da família ao longo do tempo e as transições que passou. Compreender o estágio da vida em que a família se encontra é essencial para adequar as intervenções às suas necessidades específicas. Neste domínio incluem-se as seguintes subcategorias:

   - Ciclo de Vida Familiar: inclui-se nesta subcategoria a avaliação dos estágios do ciclo de vida familiar, como a formação do casal; a fase com filhos pequenos ou adolescentes e desafios que daí podem advir; filhos adultos que ainda moram com os pais; saída dos filhos e a adaptação ao "ninho vazio" e reforma). Inclui também as tarefas específicas que estão associados a cada estágio, como educação e desenvolvimento das crianças; garantir a estabilidade financeira da família; o cuidado dos idosos e a dependência dos mesmos; manter um relacionamento saudável entre os cônjuges ao longo dos diferentes estágios. Neste contexto, o profissional de saúde deverá identificar os possíveis conflitos entre os estágios do

ciclo de vida e tarefas que estão associadas e a gestão da DM, bem como a existência de agentes facilitadores como a reforma, que podem permitir uma maior participação nas intervenções.

- Transições: refere-se à identificação das mudanças e transições significativas que a família está a experienciar ou vivenciou recentemente, como a mudança de residência; nascimento de um filho; casamento; divórcio; morte de um familiar ou reforma). Esta avaliação considera a forma como a família lida com as mudanças e transições, nas quais se destacam as estratégias de *coping* e a resiliência dos membros, que são fatores de extrema importância quando um dos membros da família é diagnosticada com DM.

3. **Domínio Funcional:** as subcategorias deste domínio fornecem aos profissionais de saúde uma compreensão detalhada do funcionamento da família no seu dia a dia, incluindo a interação e apoio existente entre os membros. Este entendimento é essencial para o desenvolvimento de intervenções que promovam o funcionamento familiar e o bem-estar de todos os membros.

Neste domínio incluem-se as seguintes subcategorias:

- Funcionamento Instrumental: nesta subcategoria do domínio do CFAM inclui-se a avaliação da gestão das atividades de vida diárias com impacto no adulto com DM. Considera como a família lida com as tarefas como cozinhar, compra de alimentos para o agregado familiar, e gestão das finanças, identificando possíveis obstáculos ou facilitadores para a gestão da DM.

  Esta subcategoria inclui os cuidados de saúde, especificamente a identificação e compreensão da forma como a família gere as necessidades ao nível de saúde dos seus membros, particularmente a pessoa que foi diagnosticada. Abrange a administração da terapêutica (injetável e/ou oral) e o acompanhamento às consultas e tratamentos necessários para a gestão da DM. É igualmente importante avaliar as rotinas e estruturas diárias que a família mantém para assegurar o seu funcionamento e organização, identificando como estas podem atuar como obstáculos ou suporte na gestão da DM.

- Funcionamento Expressivo: esta subcategoria do CFAM compreende a comunicação entre os membros da família, incluindo a clareza, frequência e a eficácia das interações verbais e não verbais, especialmente no contexto da gestão da DM. Avalia

os papéis de cada membro no suporte à pessoa diagnosticada e como estes influenciam as dinâmicas e o funcionamento familiar. Inclui também a análise das estratégias de resolução de problemas e conflitos, especialmente os relacionados com a DM, e a eficácia dessas estratégias. A expressão emocional centra-se na forma como os membros da família expressam as emoções e sentimentos uns com os outros. Inclui a capacidade dos membros se apoiarem mutuamente a nível emocional e de serem empáticos entre si. Esta subcategoria avalia também as dinâmicas de poder e influência dentro da própria família nas decisões sobre o cuidado à pessoa com diabetes, considerando também as crenças e valores que moldam as escolhas e comportamentos da família. Adicionalmente, observa a existência de alianças que possam afetar as dinâmicas, o funcionamento familiar e consequentemente a gestão da diabetes.

- Funcionamento Cognitivo: nesta subcategoria, os profissionais avaliam como a família processa a informação, isto é a forma como os membros da família adquirem, interpretam e utilizam a informação relativa à sua saúde, à gestão da Diabetes e cuidados de saúde disponíveis. No contexto da diabetes, é essencial avaliar os níveis de conhecimento da família sobre a doença, bem como a sua capacidade de compreender as instruções médicas e as recomendações relativas à gestão da diabetes. Esta avaliação permite ao profissional identificar e avaliar como o conhecimento da família influencia a sua capacidade de tomar decisões informadas sobre problemas relacionados com a gestão da diabetes e da sua saúde em geral.

PROGRAMA *JUNTOS COM A FAMÍLIA + CAPAZES*

O programa de intervenção *Juntos com a Família + Capazes* foi desenvolvido com base no Modelo de Intervenções Complexas da MRC, assegurando uma abordagem estruturada, baseada na evidência e adaptável às necessidades dos participantes. Integrando a participação ativa de profissionais de saúde, adultos com diabetes e seus familiares, o programa promove a autogestão da doença e o fortalecimento das dinâmicas familiares.

População alvo: Define-se como população alvo do programa o adulto diagnosticado com diabetes e o seu familiar. Com base na definição de família adotada pelas autoras do Modelo de Avaliação e Intervenção Familiar de Calgary (CFAIM), este programa entende por

família a pessoa que a pessoa diagnosticada com diabetes reconhece como fonte de apoio — seja ele instrumental, económico, emocional ou de outra natureza — no processo de gestão da doença, independentemente da existência de vínculos de consanguinidade ou da partilha do mesmo espaço habitacional. (Wright & Leahey, 2013).

Embora o Modelo de Intervenção Familiar de Calgary enfatize a importância de intervenções direcionadas à díade como unidade de cuidados, também contempla a possibilidade de abordar a família enquanto contexto. A escolha entre estas abordagens dependerá do contexto em que o programa de intervenção for implementado, mas, fundamentalmente, das competências e conhecimentos dos enfermeiros sobre a dinâmica familiar e o cuidado global à família. A capacitação dos profissionais para compreender e intervir no funcionamento familiar é essencial para garantir que a abordagem adotada seja eficaz e adequada às necessidades da díade. Neste âmbito, destaca-se o papel dos enfermeiros de família, cuja prática é orientada pelas competências específicas estabelecidas no Regulamento n.º 126/2011, de 18 de fevereiro, sob responsabilidade da Ordem dos Enfermeiros.

Neste contexto, importa destacar que a estrutura curricular das licenciaturas em enfermagem em Portugal nem sempre enfatiza a avaliação da família como unidade de cuidados (Barbieri-Figueiredo et al., 2021). De acordo com a mesma fonte, a análise dos conteúdos da licenciatura em enfermagem demonstra que pese embora os conteúdos sobre a família estejam integrados ao longo de todo o currículo, a abordagem mais frequentemente adotada é a da família enquanto contexto, o que limita os conhecimentos, competências e capacidades dos enfermeiros para considerarem a família como unidade de cuidados. Além disso, a prática clínica, muitas vezes focada no indivíduo, pode limitar a integração da família nos processos de cuidado. Estas lacunas podem reduzir a aptidão dos profissionais para envolverem ativamente a família como unidade de cuidados no processo de gestão da saúde, o que pode ter impacto na qualidade do suporte prestado e na efetividade das intervenções centradas na família.

Preferencialmente e à luz da legislação em vigor, Decreto-Lei n.º 28/2008, de 22 de fevereiro, alterado pelos Decretos-Leis n.os 81/2009, de 2 de abril, 102/2009, de 11 de maio, 248/2009, de 22 de setembro, 253/2012, de 27 de novembro e 137/2013 de 7 de outubro, o programa, tratando-se de uma intervenção em grupo deverá ser integrado no âmbito do plano de ação das Unidades de Cuidados na Comunidade (UCC). Estas unidades, conforme destacado no Decreto-Lei n.º 239/2015, de 14 de outubro, são reconhecidas como responsáveis pela prestação de cuidados de saúde à família e a grupos mais vulneráveis, bem

como pela promoção da educação para a saúde e pela integração das famílias em redes de apoio. No entanto, a implementação do programa poderá também ocorrer em Unidades de Saúde Familiar (USF) ou Unidade de cuidados de saúde personalizados (UCSP), desde que estas disponham dos recursos humanos e materiais adequados, com especial destaque para a formação específica dos profissionais envolvidos, garantindo assim uma intervenção eficaz e alinhada com as necessidades da díade adulto com diabetes-família.

Local onde será implementado

O programa, sempre que possível, será desenvolvido nas instalações físicas de cada ACES, ou em alternativa em locais de proximidade das populações cedidos pelos parceiros nas comunidades (espaços físicos nas juntas de freguesia, paróquias, entre outras).

Amostra: A amostra será constituída através de uma técnica de amostragem não probabilística, por conveniência, com base nos critérios previamente definidos. O processo de referenciação dos participantes deverá ser realizada através da articulação entre os enfermeiros de família, os profissionais das USF ou UCSP e os profissionais das UCC. Idealmente, o enfermeiro de família desempenhará um papel central como elo de ligação entre a família, a equipa multidisciplinar e os recursos disponíveis na comunidade, facilitando a integração dos cuidados e garantindo um acompanhamento contínuo e personalizado.

Os participantes referenciados pelos parceiros da comunidade ou que se autopropõem após a divulgação do programa, seja através das redes sociais ou em locais de proximidade, deverão, previamente à sua participação, realizar uma avaliação inicial.

A avaliação inicial a que todos os participantes serão submetidos terá como base os domínios estruturais, desenvolvimentais e funcionais da família, conforme definidos no Modelo de Avaliação Familiar de Calgary (CFAM). Este processo permitirá uma compreensão aprofundada das dinâmicas familiares, identificando fatores que influenciam a gestão da diabetes e orientando a definição de estratégias de intervenção mais ajustadas às necessidades individuais e familiares. Além disso, esta abordagem holística facilitará a identificação das especificidades do adulto diagnosticado com diabetes e da sua família, permitindo ao enfermeiro responsável pela referenciação e implementação do programa articular os diferentes recursos disponíveis, assegurando uma adaptação da intervenção de forma personalizada e eficaz.

Critérios de inclusão e exclusão dos participantes

Para a pessoa diagnosticada definem-se os seguintes critérios de inclusão:

- Idade superior a 18 anos;
- Frequentar as consultas na respetiva unidade funcional;
- Falar, escrever e compreender a língua Portuguesa;
- Sem défice cognitivo que limite a sua participação na intervenção.

Serão excluídas grávidas com Diabetes e pessoas com défices cognitivos.

Os critérios de inclusão definidos para a família incluem:

- Idade igual ou superior a 18 anos;
- Falar, escrever e compreender a língua Portuguesa;
- Sem défice cognitivo que limite a sua participação na intervenção.

A avaliação cognitiva dos participantes deverá ser realizada através de instrumentos validados para a população portuguesa, como por exemplo o Mini Mental State Examination – MMSE (Guerreiro, 1994).

O coordenador do programa, em parceria com os enfermeiros de família, deverá definir os critérios para a constituição do grupo de intervenção, com base na avaliação prévia dos participantes. Os grupos podem ser organizados de acordo com o nível de conhecimentos específicos sobre diabetes, independentemente do tempo de diagnóstico ou idade dos participantes. Adicionalmente, é possível considerar o regime terapêutico prescrito para a gestão da diabetes: o coordenador pode optar por agrupar os participantes com o mesmo regime terapêutico ou, alternativamente, reunir pessoas com diferentes regimes. Esta última opção poderá facilitar a troca de experiências, ajudando a desmistificar a complexidade muitas vezes associada à administração de terapêutica injetável.

Profissionais responsáveis pela implementação do programa

Em cada UCC, a implementação desta intervenção deverá, preferencialmente, ser assumida pelo enfermeiro coordenador do programa. Na impossibilidade de ser este profissional, a função poderá ser desempenhada por um enfermeiro especialista em Enfermagem de Saúde Comunitária.

Os profissionais responsáveis pela dinamização do programa devem possuir conhecimento abrangente sobre a autogestão da diabetes e os regimes terapêuticos.

Destaca-se ainda a importância de terem experiência e competências ao nível da entrevista motivacional e da educação terapêutica em grupo (Sociedade Portuguesa Diabetologia, 2018). A prática do profissional deve estar fundamentada na evidência científica, bem como

numa capacidade de raciocínio crítico que lhe permita reconhecer e transitar de um modelo biomédico para um modelo centrado no empoderamento da pessoa diagnosticada com diabetes e da sua família, valorizando-os enquanto peritos da sua própria saúde (Sociedade Portuguesa Diabetologia, 2018; Wright & Leahey, 2013).

Para promover a autonomia dos participantes na intervenção, o enfermeiro responsável pela dinamização das sessões deve adotar uma postura flexível, ajustando a sua prática às especificidades do grupo de intervenção. Esta adaptação inclui, sempre que necessário, a reorganização da ordem dos conteúdos e das estratégias a utilizadas.

Em diferentes módulos e de acordo com os profissionais disponíveis cada unidade de saúde e relevância para os participantes, o enfermeiro coordenador/dinamizador poderá envolver outros profissionais de enfermagem e membros da equipa multidisciplinar nas sessões (American Diabetes Association, 2023).

Estrutura do programa *Juntos com a Família + Capazes*

Duração

Seis meses no máximo

Número de sessões

O número de sessões deverá ser, no mínimo, 7 e, no máximo, 12. O coordenador do programa, em função das necessidades sentidas e/ou expressas pelos participantes em cada módulo, pode ajustar o número de sessões até ao limite máximo de 12.

Duração das sessões

As sessões deverão ter uma duração entre 60 e 120 minutos. O tempo específico de cada sessão será gerido pelo enfermeiro coordenador/dinamizador, conforme as particularidades do grupo e do módulo.

Número de participantes por sessão

Cada grupo de intervenção deverá ter no máximo 10 elementos.

Periodicidade das sessões

Sugere-se a realização de uma sessão a cada 15 dias, de modo a minimizar a sobrecarga dos participantes e a reduzir os custos de transporte. No entanto, o enfermeiro coordenador/dinamizador poderá ajustar esta periodicidade em acordo com os participantes.

Agendamento das sessões

Na sessão zero, o enfermeiro coordenador/dinamizador, em parceria com os participantes, deverá agendar as datas e horários de todas as sessões. Este planeamento prévio ajudará os participantes a conciliar os seus compromissos pessoais e familiares com a participação nas sessões.

Estrutura do programa

O programa possui uma estrutura modular que inclui **sete módulos mandatórios**. Deverá iniciar-se com o "Módulo zero: Baseline" e concluir-se com o "Módulo final: Sessão de Encerramento", que correspondem aos *timings* de recolha de dados pré e pós - intervenção. O período entre o Módulo Zero e Módulo Final é de **seis meses**.

Os outros cinco módulos têm a seguinte designação:

- Transformar Hábitos: Caminhos para um Estilo de Vida Saudável na gestão da Diabetes;
- Alimentação Equilibrada: Uma Abordagem Saudável para a gestão da Diabetes;
- Movimento e Saúde: A Importância da Atividade Física na Gestão da Diabetes;
- Família e Comunicação: Dinâmicas Familiares Essenciais na Gestão da Diabetes Mellitus;
- Diabetes Mellitus: Compreender, Autovigiar e Superar Possíveis Complicações para uma Vida Plena.

O enfermeiro coordenador/dinamizador, respeitando as diretrizes do programa e com base na avaliação prévia dos participantes e nas necessidades expressas ou identificadas durante as sessões, pode personalizar a intervenção para cada grupo específico, em parceria efetiva com os participantes. Esta personalização inclui a definição da ordem dos cinco módulos, o número de sessões dedicadas a cada módulo e a adaptação da duração de cada sessão aos conteúdos abordados e às necessidades dos participantes.

Formato das sessões

As sessões deverão ser realizadas preferencialmente em formato presencial em local próximo e de fácil acesso aos participantes. Como alternativa, poderá ser utilizada a videochamada, com recurso por exemplo ao *Zoom*, desde que todos os participantes do grupo concordem e que estejam reunidas as condições necessárias, como acesso aos meios e competências digitais adequadas.

Estratégias sugeridas

As estratégias sugeridas incluem:

- Metodologias de ensino tradicionais combinadas com estratégias dinâmicas em grupo (Deverts et al., 2022). Sugere-se a participação ativa dos participantes na identificação e resolução de questões relativas a cada tema abordado em cada módulo (Zhang et al., 2022), utilizando métodos de exposição verbal de conteúdos (Pamungkas et al., 2017; Torenholt et al., 2014). Em alternativa poderá ser utilizado o modelo pedagógico de ensino à distância (Fleming et al., 2020; Kerr et al., 2019; Pérez-Aldana et al., 2021). O recurso a novas tecnologias (*Zoom* ou *Teams*) terá que ser avaliado pelo enfermeiro coordenador/dinamizador de acordo com as características do grupo, nomeadamente as suas competências digitais, para além do seu acesso à internet e a equipamentos adequados;
- Jogos interativos em grupo (Vissenberg et al., 2017);
- Prática de exercício físico em grupo;
- Distribuição de um bloco e caneta no final do primeiro módulo, para que os participantes possam no seu dia a dia apontar questões que surjam e que poderão ser esclarecidas na sessão seguintes;
- Distribuição de material de apoio (guias de apoio à gestão da Diabetes[1]) aos participantes para posterior consulta e esclarecimento de dúvidas que possam surgir no seu quotidiano (Deverts et al., 2022; Luthfa & Ardian, 2019; Pamungkas et al., 2017; Soares, 2019);
- Distribuição do endereço eletrónico do blog (será criado para o programa) para onde estarão resumidos os temas abordados nas sessões;
- Telefonemas de motivação a serem realizados durante a intervenção e após o término da mesma (follow-up a ser realizado durante os seis meses subsequentes). Recomenda-se aos profissionais a utilização dos princípios da entrevista motivacional durante a realização do telefonema (Bender et al., 2017; Gomes et al., 2017; Liao et al., 2020; McEwen et al., 2019; McEwen et al., 2017; Nutchanath Wichit et al., 2017). Durante o período de implementação da intervenção estão previstos 6 telefonemas de motivação mensais com uma duração máxima de 15 minutos. No período de *follow-up* estão igualmente previstos 6 telefonemas, com duração máxima de 20 minutos cujo objetivo é a motivação dos participantes e o esclarecimento de dúvidas. Os telefonemas serão realizados pelo enfermeiro coordenador/ dinamizador do programa com a pessoa diagnosticada, pese embora possa ser acordado entre o profissional e os participantes

alguma alteração a esta estratégia. Como exemplo, poderão ser acordados momentos para a realização dos telefonemas em que esteja presente para além da pessoa diagnosticada o familiar.

- Momentos de partilha no final das sessões, nos quais todos os participantes serão incentivados a fazer um breve feedback da sessão realizada;
- Possibilidade de criação de plataformas nas redes sociais para e de grupos de partilha e troca de experiências, após a sessão zero (Bender et al., 2017; Kerr et al., 2019; Pérez-Aldana et al., 2021) . A utilização desta estratégia e a seleção das próprias plataformas será realizada com os participantes, de acordo com as suas preferências e literacia digital. Todas as páginas criadas terão a mesma designação, garantindo-se que o conteúdo partilhado e o momento de partilha será igual, independentemente da plataforma selecionada.

O programa *Juntos com a família + Capazes*, ao romper com o modelo paternalista de cuidados e com a definição unilateral de metas, integra diferentes estratégias desenvolvidas para promover a independência e melhorar a interface entre os profissionais e as pessoas diagnosticadas e suas famílias. O objetivo é fornecer um suporte estruturado e regular, facilitando a tomada de decisões e a identificação e superação das barreiras que surgem no quotidiano. Através da parceria estabelecida entre os participantes, o enfermeiro coordenador/dinamizador e o enfermeiro de família, as pessoas diagnosticadas terão a oportunidade de definir objetivos SMART individuais (*Specific, Measurable, Achievable, Relevant, and Time-Bound*), para além dos objetivos definidos em grupo no âmbito da intervenção (Magtoto, 2023). A concretização destes objetivos será apoiada pelo enfermeiro coordenador/ dinamizador, através da realização de telefonemas de motivação a realizar com a pessoa com diabetes.

Reuniões entre investigador e enfermeiros coordenadores/facilitadores

Estão programadas reuniões entre o investigador, o enfermeiro responsável pela dinamização do programa e outros membros da equipa multidisciplinar. Estas reuniões integram o processo de capacitação dos profissionais, abordando os princípios orientadores do programa, o seu modelo teórico e as informações relevantes ou dúvidas que possam surgir. As reuniões terão início antes da implementação da intervenção e continuarão ao longo de todo o processo, com uma periodicidade ajustada às necessidades identificadas tanto pelos profissionais quanto pelo investigador.

Resultados Esperados e Avaliação dos Ganhos em Saúde

A participação no programa de intervenção *Juntos com a Família + Capazes* espera-se que resulte em ganhos significativos em saúde para a pessoa com diabetes e a sua família, ajustados às necessidades específicas do grupo de intervenção. Estes ganhos incluem uma maior literacia em saúde, com ênfase no conhecimento específico sobre a diabetes e uma maior adesão ao regime terapêutico. Além disso, prevê-se uma melhoria na autoeficácia e na qualidade de vida dos participantes, bem como no funcionamento familiar, promovendo um suporte mais coeso e numa rede de apoio mais efetiva entre os membros da família.

Para avaliar a efetividade do programa, será realizada uma avaliação prévia e posterior à sua implementação, recorrendo a instrumentos validados para a população portuguesa. Estes instrumentos permitirão monitorizar os ganhos em saúde e ajustar as intervenções conforme necessário, garantindo que a resposta às necessidades da pessoa com diabetes e da sua família seja personalizada e efetiva.

Os instrumentos de avaliação incluem:

- Questionário de avaliação clínica que incluem: o Índice de Massa Corporal (IMC); hemoglobina glicada (HbA1c); perímetro abdominal; pressão arterial (mínima e máxima); consumo de álcool (número de copos /dia) e os hábitos tabágicos (número de cigarros/dia). De igual forma também serão avaliados: o consumo regular de uma dieta equilibrada e adaptada à gestão da diabetes; prática de exercício físico regular (número de horas/ semana);
- Escala de Conhecimento da Diabetes – DKT – que avalia o conhecimento específico sobre a diabetes e a sua gestão (Azevedo & Santago, 2016; Fitzgerald et al., 1998). Esta escala é pontuada com base no número de respostas corretas, demorando cerca de 15 minutos a ser preenchida (Azevedo e Santiago, 2016). Importa referir que, no caso de pessoas não insulinotratadas, apenas os primeiros 14 itens do instrumento são aplicáveis, sendo o questionário completo indicado para pessoas insulinotratadas (Fitzgerald et al., 1998).
- Escala de Capacidade de Controlo da Diabetes – DES-SF (Versão breve) – que avalia globalmente a autoeficácia psicossocial relacionada com a diabetes (Anderson et al., 2000; Aveiro et al., 2015). Cada resposta tem opções pontuadas entre 1 (discordo completamente) e 5 (concordo completamente), sendo o score final obtido pela média das pontuações dos oito itens da escala.

- Questionário de Avaliação de Ganhos em Saúde – EQ-5D-5L – que avalia a informação sobre a Qualidade de Vida Relacionada com a Saúde (Ferreira et al., 2014; Ferreira et al., 2013). Este questionário utiliza um sistema classificativo composto por cinco dimensões: mobilidade, cuidados pessoais, atividades habituais, dor/mal-estar e ansiedade/depressão. Cada resposta inclui cinco níveis de severidade: sem problemas (nível 1); problemas ligeiros (nível 2); problemas moderados (nível 3); problemas graves (nível 4) e problemas extremos (nível 5), permitindo descrever o estado de saúde da pessoa. O índice global do instrumento é gerado por um algoritmo com base nas preferências das respostas das cinco dimensões. Este índice EQ-5D varia numa escala de 1 (saúde perfeita) a 0 (morte), podendo também apresentar valores negativos, que indicam estados de saúde considerados piores do que a morte.
- Instrumento de Avaliação do Funcionamento Familiar relacionado com a diabetes – FIAD-PT – avalia o funcionamento familiar relacionado com a diabetes, mais especificamente o envolvimento de familiares e amigos na gestão da diabetes em adultos (Mayberry et al., 2019) Soares et al., 2024). Este instrumento avalia duas formas de envolvimento familiar na autogestão da diabetes: os comportamentos de suporte, medidos através de nove itens (1, 3, 4, 7, 8, 10, 11, 14, 16), e os comportamentos obstrutivos, ou seja, o envolvimento prejudicial, avaliados com sete itens (2, 5, 6, 9, 11, 13, 15). O questionário avalia ações observáveis relacionadas com os cuidados de autogestão da diabetes nos últimos 30 dias, permitindo gerar duas pontuações separadas que representam a frequência de cada tipo de apoio recebido.

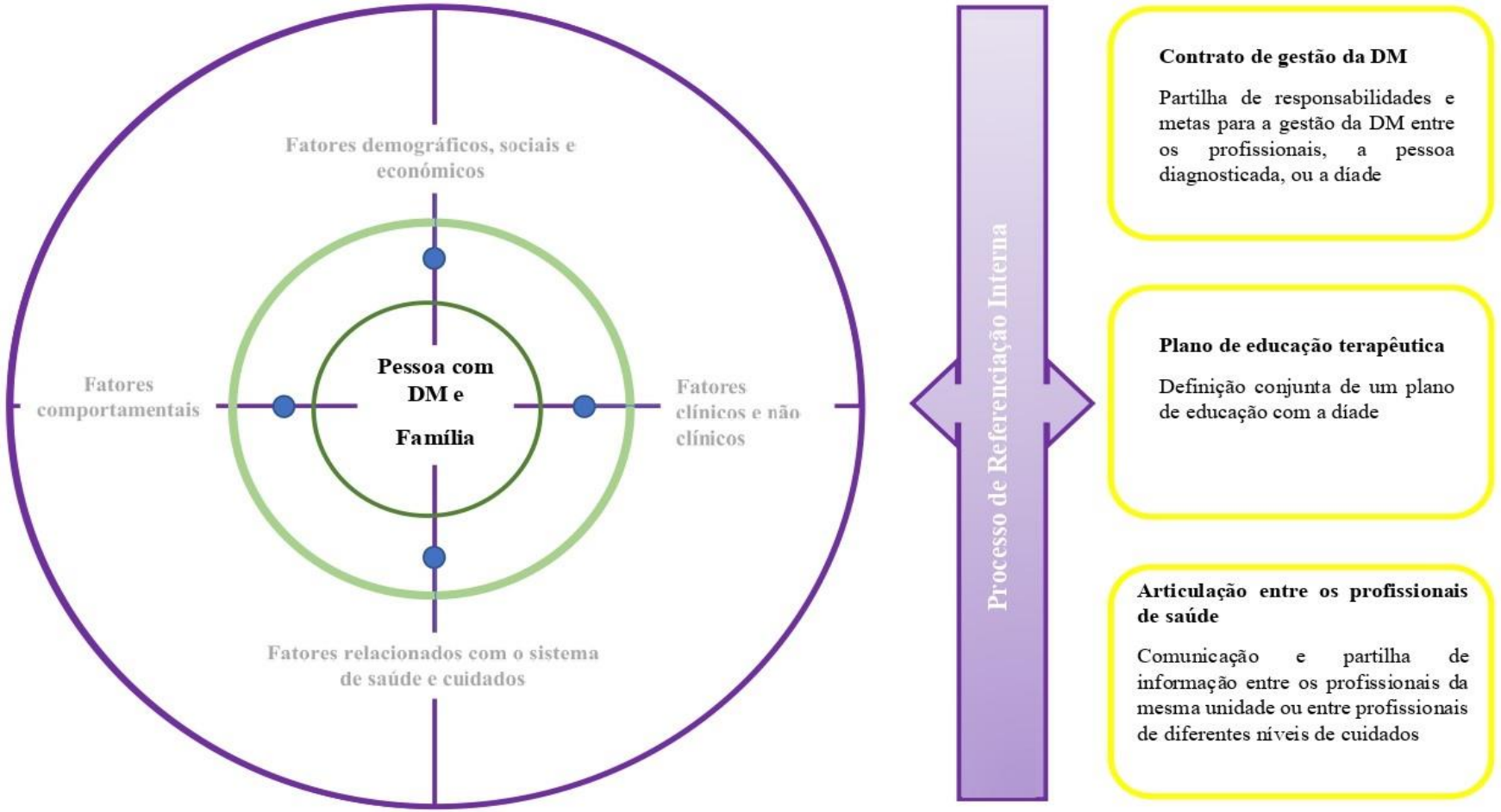

Figura 1. Construção do Plano Individual de Cuidados

Tabela 1. Guia Orientador do Programa *Juntos com a Família + Capazes*

PROGRAMA DE INTERVENÇÃO *JUNTOS COM A FAMÍLIA + CAPAZES*: DESCRIÇÃO DETALHADA DOS MÓDULOS
MÓDULO 0: BASELINE
OBJETIVOS DE APRENDIZAGEM - Descrever o programa *Juntos com a Família + Capazes*, explorando os seus objetivos, estrutura e módulos; - Analisar os módulos que constituem o programa e a sua aplicação prática; - Definir e aplicar objetivos SMART (Específicos, Mensuráveis, Alcançáveis, Relevantes e Temporais), compreendendo a sua importância para o alcance de metas individuais e de grupo; - Identificar e estabelecer, em grupo, os objetivos SMART que irão orientar a intervenção, reconhecendo o seu impacto na saúde e bem-estar dos participantes; - Compreender as variáveis clínicas e não clínicas relacionadas com a gestão da diabetes e o seu papel na prevenção de complicações associadas; - Conhecer os momentos e métodos de recolha de dados para a avaliação das variáveis clínicas e não clínicas ao longo da intervenção; - Reconhecer a importância da autonomia e da parceria com os profissionais de saúde ao longo do programa; - Valorizar a participação ativa da díade (pessoa com diabetes e familiar) nas sessões e a importância do suporte mútuo; - Incentivar o registo de questões e reflexões ao longo das sessões para promover o esclarecimento contínuo e a adaptação das práticas de autogestão.

CONTEÚDOS PROGRAMÁTICOS

- Programa *Juntos com a Família + Capazes*: Visão geral dos objetivos, estrutura das sessões e módulos;
- Objetivos SMART: Importância e definição para alcançar metas específicas e personalizadas;
- Variáveis Clínicas em Avaliação: Pressão arterial (sistólica e diastólica), hemoglobina glicada (HbA1c), perímetro abdominal, consumo de álcool (número de copos/dia) e hábitos tabágicos (número de cigarros/dia);
- Indicadores Não Clínicos: Consumo de uma dieta equilibrada e saudável, prática regular de exercício físico (número de horas/semana), hábitos de vida saudáveis (alimentação e atividade física), conhecimento sobre diabetes, qualidade de vida, autoeficácia e funcionamento familiar;
- Suporte Social: Importância das redes de apoio familiar e social para a gestão efetiva da diabetes;
- Participação Ativa e Empoderamento: Envolvimento dos participantes como especialistas na sua própria saúde, promovendo a autoconfiança e a tomada de decisão informada;
- Registo de Questões e Reflexões: Incentivo ao registo de dúvidas e observações para esclarecimento nas sessões e consultas subsequentes;
- Motivação e Adesão ao Tratamento: Papel fundamental da motivação para manter a adesão ao regime terapêutico e para a construção de um estilo de vida saudável e sustentável.

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MÓDULOS

TRANSFORMAR HÁBITOS: CAMINHOS PARA UM ESTILO DE VIDA SAUDÁVEL NA GESTÃO DA DIABETES

ALIMENTAÇÃO EQUILIBRADA: UMA ABORDAGEM SAUDÁVEL PARA A GESTÃO DA DIABETES

MOVIMENTO E SAÚDE: A IMPORTÂNCIA DA ATIVIDADE FÍSICA NA GESTÃO DA DIABETES

FAMÍLIA E COMUNICAÇÃO: DINÂMICAS FAMILIARES ESSENCIAIS NA GESTÃO DA DIABETES MELLITUS

DIABETES MELLITUS: COMPREENDER, AUTOVIGIAR E SUPERAR POSSÍVEIS COMPLICAÇÕES PARA UMA VIDA PLENA

MÓDULO: TRANSFORMAR HÁBITOS: CAMINHOS PARA UM ESTILO DE VIDA SAUDÁVEL NA GESTÃO DA DIABETES

OBJETIVOS DE APRENDIZAGEM

- Compreender o conceito de estilo de vida saudável e o seu impacto na saúde física e mental;
- Identificar fatores pessoais, familiares e sociais que influenciam a adesão a um estilo de vida saudável;
- Explorar a relação entre um estilo de vida saudável e a melhoria do bem-estar e qualidade de vida dos participantes;
- Desenvolver competências de autovigilância e autogestão, promovendo a autonomia e a confiança na gestão da diabetes;
- Reconhecer a importância da participação e suporte de toda a família na adaptação a um estilo de vida saudável e na gestão da diabetes;
- Compreender a relevância do suporte social e comunitário para a motivação e manutenção de hábitos saudáveis;
- Identificar estratégias para lidar com os desafios e obstáculos no quotidiano relacionados com a diabetes;
- Desenvolver estratégias para o registo de questões e reflexões ao longo das sessões.

CONTEÚDOS PROGRAMÁTICOS

- Estilo de Vida Saudável: Definição e impacto na vida da pessoa e da família, com foco em benefícios físicos, emocionais e sociais;
- Benefícios da Adesão Familiar a um Estilo de Vida Saudável: Motivação, superação de barreiras e estratégias de mudança gradual;
- Determinantes Sociais de Saúde: Influência dos fatores sociais, económicos e culturais no bem-estar individual e familiar;
- Suporte Social e Familiar: Importância do envolvimento de familiares e comunidade na gestão da diabetes e na motivação para uma vida saudável;
- Comunicação e Relações Interpessoais: Estratégias de comunicação eficaz entre os membros da família para melhorar o apoio mútuo;
- Autovigilância e Autogestão da Diabetes: Importância e técnicas para a gestão diária da diabetes, prevenindo complicações associadas;
- Saúde Mental e Bem-Estar: Reconhecimento das emoções associadas à gestão da diabetes e desenvolvimento de estratégias para lidar com o stress, ansiedade e outros desafios emocionais;
- Recursos Comunitários e Redes de Apoio: Identificação de recursos disponíveis nos vários contextos (pessoais, sociais, económicos e culturais) para apoiar um estilo de vida saudável e a gestão da diabetes.

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MÓDULO: ALIMENTAÇÃO EQUILIBRADA: CAMINHOS PARA UM ESTILO DE VIDA SAUDÁVEL NA GESTÃO DA DIABETES

OBJETIVOS DE APRENDIZAGEM

- Compreender os princípios básicos de uma alimentação saudável e o seu papel na gestão da diabetes;
- Identificar as necessidades nutricionais específicas de um adulto com diabetes e adaptar as escolhas alimentares;
- Reconhecer estratégias práticas para promover uma nutrição consciente no quotidiano familiar;
- Identificar o impacto das escolhas alimentares nos níveis de glicemia e na saúde geral;
- Desenvolver competências para planear e preparar refeições saudáveis e acessíveis;
- Reconhecer a influência das questões de género e papéis sociais na adesão a uma alimentação saudável;
- Compreender a importância de ler e interpretar rótulos para fazer escolhas alimentares informadas;
- Desenvolver estratégias para escolhas alimentares saudáveis em restaurantes e eventos festivos;
- Reconhecer fatores contextuais e culturais que influenciam as escolhas alimentares individuais e familiares;
- Motivar os participantes a adotar hábitos alimentares saudáveis e sustentáveis;
- Valorizar o registo de dúvidas e reflexões para facilitar o acompanhamento nas sessões seguintes.

CONTEÚDOS PROGRAMÁTICOS

- Princípios de uma Alimentação Saudável: Importância na gestão da diabetes, grupos alimentares da roda dos alimentos, e a proporção recomendada de cada grupo;

- Conceitos de Nutrição e Alimentação: Alimentação completa, equilibrada e variada; impacto na saúde familiar e na prevenção de complicações;
- Planeamento Familiar de Refeições: Seleção de alimentos e preparação de refeições saudáveis, com exemplos práticos e receitas adaptadas;
- Leitura de Rótulos e Escolhas Alimentares Informadas: Composição dos alimentos, nutrientes a evitar, e análise de alimentos pré-cozinhados e industrializados;
- Influência dos Géneros e Papéis Sociais na Nutrição Familiar: Facilitadores e barreiras que impactam as escolhas individuais e familiares;
- Determinantes de Saúde e Contextos Alimentares: Fatores sociais, económicos e culturais que condicionam as escolhas alimentares;
- Alimentação Fora de Casa e em Eventos Festivos: Estratégias para fazer escolhas saudáveis em contextos variados;
- Monitorização do Peso e Perímetro Abdominal: Importância do acompanhamento regular para a gestão da diabetes;
- Índice Glicémico dos Alimentos: Identificação dos sinais de hipoglicemia e hiperglicemia, e estratégias de atuação.

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MÓDULO: MOVIMENTO E SAÚDE: A IMPORTÂNCIA DA PRÁTICA DE EXERCÍCIO FÍSICO NA GESTÃO DA DIABETES

OBJETIVOS DE APRENDIZAGEM

- Compreender a diferença entre exercício físico regular, atividade física laboral e sedentarismo.
- Identificar os benefícios do exercício físico regular na gestão da diabetes e no bem-estar geral;
- Reconhecer a importância de ajustar a intensidade e prática do exercício físico às necessidades e condições de saúde individuais, promovendo uma abordagem personalizada;
- Compreender os cuidados necessários para praticar exercício físico de forma segura;
- Compreender o impacto do exercício físico nos níveis de glicemia e a importância de monitorizar esses níveis antes e após a prática;
- Identificar os sinais de hipoglicemia e hiperglicemia durante a atividade física e as ações adequadas para cada caso;
- Identificar fatores contextuais que facilitam ou dificultam a prática de exercício físico regular;
- Reconhecer como as questões de género e os papéis sociais podem influenciar a adesão à prática de exercício físico;
- Identificar estratégias para promover a adesão ao exercício físico regular em diferentes contextos;
- Valorizar o registo de dúvidas e observações durante as sessões para facilitar o acompanhamento e esclarecimento em encontros futuros.

CONTEÚDOS PROGRAMÁTICOS

- Literacia Física: Conceitos e características de exercício físico estruturado, atividade física laboral e sedentarismo;
- Benefícios do Exercício Físico Regular: Importância e impacto positivo na gestão da diabetes e na saúde dos adultos com diabetes e suas famílias;
- Prática Regular de Exercício Físico: Impacto na gestão da diabetes e nos níveis de glicemia;

- Prescrição Individualizada de Exercício: Objetivos personalizados para cada participante, tendo em conta condições de saúde e preferências individuais;
- Integração com o Regime Terapêutico: Adaptação da intensidade do exercício físico com autovigilância dos níveis de glicemia;
- Determinantes em Saúde e Contexto: Fatores dos diferentes contextos que influenciam a prática de exercício físico e estratégias para lidar com esses fatores;
- Influência dos Géneros e Papéis Sociais: Facilitadores e obstáculos que afetam a prática de exercício físico nas escolhas individuais e familiares;
- Cuidados na Prática de Exercício Físico: Recomendações de segurança antes, durante e após o exercício.

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MÓDULO: FAMÍLIA E COMUNICAÇÃO: DINÂMICAS FAMILIARES ESSENCIAIS NA GESTÃO DA DIABETES MELLITUS

OBJETIVOS DE APRENDIZAGEM

- Compreender o impacto do diagnóstico de diabetes nos vários membros da família.
- Reconhecer a importância do envolvimento ativo da família na gestão da diabetes, incluindo a participação em consultas e educação terapêutica.
- Identificar as dinâmicas familiares, papéis sociais e de género que influenciam a gestão da diabetes.
- Distinguir comportamentos de suporte e comportamentos que dificultam o apoio familiar na gestão da diabetes.
- Identificar os aspetos inerentes à multiculturalidade familiar e as suas implicações na gestão da diabetes.
- Analisar o conceito de comunicação, as suas características e o impacto nos comportamentos dos membros da família.
- Reconhecer a importância de uma comunicação eficaz e colaborativa na gestão familiar da diabetes.
- Compreender o papel de um ambiente de apoio e colaboração familiar na adesão a um estilo de vida saudável.
- Desenvolver competências e estratégias para uma comunicação eficaz e positiva no contexto familiar.
- Identificar os conflitos familiares comuns na gestão da diabetes e desenvolver técnicas de resolução dos mesmos.
- Valorizar o registo de questões levantadas nas sessões para facilitar o acompanhamento em encontros futuros.

CONTEÚDOS PROGRAMÁTICOS

- Diagnóstico de Diabetes no Adulto: Impacto emocional e prático nos vários membros da família;
- Envolvimento Familiar na Gestão da Diabetes: Importância e impacto do apoio familiar na gestão da diabetes;

- Comportamentos de Suporte e Comportamentos Obstrutivos: Identificação de comportamentos que promovem ou dificultam a gestão da diabetes;
- Suporte Social Familiar: Diferenças entre o suporte sentido, expresso e as expectativas dos membros da família;
- Determinantes Sociais da Saúde: Impacto de fatores sociais na gestão da diabetes;
- Valores e Tradições Familiares: Influência dos valores e tradições familiares no suporte e gestão da diabetes;
- Papéis Sociais, Questões de Género e Dinâmicas Familiares: Impacto no suporte familiar e na gestão da diabetes;
- Padrões de Comunicação Familiar: Impacto da comunicação nas dinâmicas familiares, autogestão e adoção de estilos de vida saudável;
- Comunicação Eficaz: Técnicas de escuta ativa, estabelecimento de limites e linguagem clara para promover um ambiente de apoio;
- Conflitos Familiares na Gestão da Diabetes: Técnicas de resolução efetivas para promover a cooperação e reduzir tensões.

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MÓDULO: DIABETES MELLITUS: COMPREENDER, AUTOVIGIAR E SUPERAR POSSÍVEIS COMPLICAÇÕES PARA UMA VIDA PLENA

OBJETIVOS DE APRENDIZAGEM

- Compreender como a DM afeta as pessoas diagnosticadas, como causas, tipos e mecanismos da doença, e as diferenças entre diabetes tipo 1 e tipo 2;
- Reconhecer a importância de desenvolver competências pessoais de autovigilância para prevenir complicações associadas à diabetes;

- Compreender a importância de identificar sinais e sintomas de complicações e agir preventivamente;
- Identificar as complicações específicas que podem surgir e as mudanças no estilo de vida que ajudam a preveni-las;
- Desenvolver competências de autovigilância e autonomia para uma gestão efetiva da diabetes;
- Desenvolver habilidades de autonomia e tomada de decisão para identificar e responder a situações de urgência relacionadas com a diabetes;
- Identificar materiais de apoio e tecnologias atuais que podem ser utilizados na autogestão da diabetes;
- Compreender como adaptar o uso de tecnologias de apoio às necessidades e nível de literacia digital de cada pessoa e da família;
- Reconhecer a importância do envolvimento familiar, dos profissionais e dos recursos comunitários como rede de apoio para a autogestão;
- Reconhecer o impacto da diabetes na saúde mental da pessoa diagnosticada e da família;
- Identificar as manifestações psicológicas comuns associadas ao diagnóstico e à gestão da diabetes;
- Desenvolver estratégias para reduzir o impacto do stress, ansiedade e depressão associados à diabetes;
- Compreender a importância de estabelecer, em parceria com os profissionais, um plano de gestão individualizado da diabetes;
- Valorizar o registo de questões durante as sessões para facilitar o esclarecimento e o acompanhamento em encontros futuros.

CONTEÚDOS PROGRAMÁTICOS

- Fundamentos da Diabetes: Efeitos do diagnóstico, causas, tipos e mecanismos da doença;
- Autovigilância e Complicações da Diabetes: Identificação de sinais e sintomas, prevenção e tratamento das principais complicações;
- Situações de Urgência e Gestão da Diabetes: Promoção da autonomia para identificar e atuar em situações de urgência;

- Autogestão e Promoção da Autonomia: Desenvolvimento de competências para a tomada de decisão informada e utilização de redes de apoio adaptadas a cada contexto;

- Tecnologias e Materiais de Apoio na Autogestão da Diabetes: Exploração das opções de apoio técnico e sua adaptação ao contexto pessoal;

- Impacto da Diabetes na Saúde Mental: Efeitos na pessoa com diabetes e na família, incluindo psicopatologias mais comuns e sinais e sintomas;

- Promoção do Bem-Estar Emocional: Estratégias para promover a saúde mental e o bem-estar emocional**.**

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MÓDULO FINAL: SESSÃO ENCERRAMENTO

OBJETIVOS DE APRENDIZAGEM

- Compreender o impacto da participação no programa nas variáveis clínicas dos participantes;
- Avaliar o impacto do programa nos indicadores clínicos e no cumprimento dos objetivos SMART definidos para o grupo de intervenção;
- Realizar uma avaliação qualitativa do programa, identificando áreas de sucesso e oportunidades de melhoria;
- Reconhecer a importância de manter um estilo de vida saudável após a conclusão do programa;
- Compreender o papel do suporte social na manutenção de hábitos saudáveis e na gestão da diabetes;
- Valorizar o registo de questões e reflexões que surgirem no quotidiano para serem discutidas em telefonemas de follow-up e nas consultas de acompanhamento.

CONTEÚDOS PROGRAMÁTICOS

- Objetivos SMART: Avaliação no contexto do grupo de intervenção psicoeducativa;
- Programa *Juntos com a Família + Capazes*: Avaliação qualitativa dos objetivos, sessões e módulos;
- Variáveis Clínicas em Avaliação: Medição de pressão arterial (sistólica e diastólica), hemoglobina glicada (HbA1c), perímetro abdominal, consumo de álcool (número de copos/dia) e hábitos tabágicos (número de cigarros/dia);
- Indicadores Não Clínicos: Avaliação da adesão a uma dieta equilibrada e saudável, prática regular de exercício físico (número de horas/semana), hábitos de vida saudável (alimentação e atividade física), conhecimento sobre diabetes, qualidade de vida relacionada com a saúde, autoeficácia e funcionamento familiar;
- Suporte Social: Importância do suporte social na continuidade da gestão da diabetes e na manutenção de um estilo de vida saudável.

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TELEFONEMAS DE MOTIVAÇÃO E DE FOLLOW-UP

OBJETIVO DE APRENDIZAGEM

- Refletir sobre os progressos e desafios vivenciados pelos participantes ao longo da intervenção, promovendo um espaço de partilha e aprendizagem mútua;
- Reavaliar as variáveis em estudo com foco em como as mudanças impactaram a qualidade de vida e as dinâmicas familiares;
- Avaliar os objetivos SMART considerando a concretização, os facilitadores e os obstáculos encontrados, e adaptar estratégias para continuidade;
- Explorar de forma qualitativa as perceções dos participantes sobre o programa, valorizando as experiências individuais e familiares para aprimorar futuras intervenções;
- Revisitar a importância de práticas saudáveis no quotidiano de forma prática e acessível, alinhando-as aos valores, rotinas e contexto familiar;
- Reforçar a relevância do suporte social para a continuidade dos resultados, identificando fontes de apoio dentro e fora da família.

CONTEÚDOS PROGRAMÁTICOS

- Reflexão sobre a Experiência e Progresso:
    - Discussão sobre mudanças percebidas no bem-estar individual e familiar ao longo do programa;
    - Identificação de barreiras e facilitadores no cumprimento das metas estabelecidas.
- Avaliação do Conhecimento e Competências:
    - Revisão do conhecimento adquirido sobre diabetes, com ênfase em como ele foi integrado no dia-a-dia;
    - Exploração do impacto do programa na autoeficácia, no envolvimento familiar e na qualidade de vida.
- Estilos de Vida Sustentáveis:
    - Reflexão sobre hábitos de alimentação e atividade física que se tornaram parte da rotina;
    - Sugestões práticas e acessíveis para ajustar ou manter hábitos saudáveis no contexto de cada participante e sua família.
- Revisão e Celebração de Objetivos SMART Concretizados;
    - Reconhecimento das metas alcançadas e celebração de pequenas e grandes conquistas;
    - Ajuste de metas futuras, mantendo-as específicas, mensuráveis e alinhadas às prioridades familiares.
- Gestão Sustentada da Diabetes;
    - Discussão sobre os benefícios de continuar a gestão ativa da diabetes;
    - Exploração de estratégias para enfrentar desafios, como motivação em longo prazo e suporte social.
- Fortalecimento do Suporte Social:
    - Identificação de fontes de apoio na família e na comunidade;
    - Estratégias para envolver a rede de apoio no dia-a-dia, promovendo um ambiente de encorajamento e colaboração;
    - Avaliação do Programa e Sugestões.
- Discussão qualitativa sobre o impacto do programa: o que funcionou bem e o que poderia ser melhorado.
- Sugestões para adaptar futuras intervenções às necessidades específicas dos participantes.

WHATSAPP E REDES SOCIAIS

OBJETIVOS GERAIS:

- Promover a partilha de experiências e o apoio mútuo entre os participantes;
- Reforçar os conteúdos abordados nas sessões do programa de forma acessível e interativa;
- Facilitar o esclarecimento de dúvidas de forma célere, promovendo o envolvimento contínuo;
- Incentivar a reflexão e a aplicação prática das aprendizagens no quotidiano.

CONTEÚDOS PROGRAMÁTICOS GRUPO WHATSAPP

- Partilha de Experiências e Estratégias:
    - Incentivar os participantes a partilharem os desafios diários e as estratégias utilizadas para os ultrapassar;
    - Utilizar perguntas semanais orientadoras (ex.: "Que pequenas conquistas alcançaram esta semana na gestão da diabetes?").
- Esclarecimento de Dúvidas:
    - Responder de forma clara e empática às dúvidas práticas ou relacionadas com os conteúdos das sessões;
    - Promover o apoio mútuo entre os membros do grupo (ex.: sugestões práticas sobre alimentação ou exercício físico).
- Motivação e Reflexão:
    - Partilhar mensagens motivacionais, pequenos desafios ou lembretes (ex.: "Hoje é um ótimo dia para uma caminhada em família!").
    - Reforçar os comportamentos saudáveis ou progressos partilhados no grupo.

CONTEÚDOS PROGRAMÁTICOS REDES SOCIAIS

- Reforço dos Conteúdos das Sessões:
    - Publicar resumos semanais sobre os temas abordados nas sessões do programa;
    - Partilhar de infográficos ou vídeos explicativos sobre diabetes, estilos de vida saudáveis e gestão emocional da doença.
- Recursos Práticos.
    - Dicas sobre alimentação saudável (ex.: receitas simples e acessíveis);
    - Sugestões para integrar a atividade física na rotina familiar;
    - Estratégias para melhorar a comunicação e o suporte no seio da família.
- Envolvimento e Interação:
    - Publicar de sondagens ou questões para incentivar a participação (ex.: "Qual é o maior desafio que enfrentam no planeamento das refeições?");
    - Partilhar histórias de sucesso (com autorização dos participantes), para inspirar e motivar o grupo.
- Promoção de Suporte Social
    - Incentivar a interação entre membros do grupo, criando uma rede de apoio;
    - Promover discussões sobre o impacto social e familiar da diabetes, promovendo empatia e compreensão.
- Monitorização e Moderação
    - Garantir que os conteúdos partilhados sejam seguros, respeitosos e alinhados aos objetivos do programa;
    - Apoiar na resolução de eventuais conflitos ou mal-entendidos no grupo.

1. **Guia para viver com Diabetes**

Guia disponível na língua Portuguesa, tendo sido desenvolvido no âmbito do programa intitulado "Juntos é mais Fácil", tendo sido avaliado de forma muito positiva pela entidade financiadora. A implementação em Portugal teve a organização da Associação Protetora dos Diabéticos de Portugal (APDP) e Sociedade Portuguesa Diabetologia (SPD) com o apoio da Direção Geral da Saúde (DGS) no âmbito do Programa Nacional de Prevenção e Combate da Diabetes, financiado pela Fundação Calouste Gulbenkian.

2. **JOGO "Diabetes: importância do exercício físico":**

- Serão criadas questões sobre a importância do exercício físico na gestão da DM;
- Os participantes de cada grupo deverão responder às questões colocadas enquanto grupo. No final as diferentes questões e as respostas serão analisadas em grupo.
- O facilitador irá responder às questões inicialmente colocadas e dúvidas dos participantes.

3. **JOGO "Alimentação Saudável":**

- A cada participante serão distribuídos cartões aleatórios com ilustração de variados alimentos;
- O participante deverá distribuir os cartões por três caixas com cores e rótulos diferentes "vermelho – não aconselhável incluir na dieta"; "amarelo – ingerir em pequenas quantidades de forma esporádica"; "verde – considerado saudável e que deverá ser ingerido de forma regular".
- Em grupo, os participantes deverão distribuir os cartões que alocaram nas 2 "caixas verde e amarela", elaborando alternativas saudáveis para as diferentes refeições do dia a dia;
- As diferentes opções realizadas pelos participantes serão abordadas em grupo.

4. **JOGO "Comunicar de forma objetiva e eficaz"**

- Os participantes são desafiados a participarem no exercício "Role-playing";
- O facilitador sugere alguns possíveis cenários do quotidiano para treino de estratégias e formas de comunicação eficazes. Salienta-se neste jogo a importância da linguagem não verbal;
- Os participantes são incentivados a sugerirem cenários para o "Role-playing".

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CAPÍTULO VI – DISCUSSÃO

A diabetes mellitus, pela sua crescente prevalência e as complicações associadas, constitui uma prioridade incontornável em saúde pública, estando no centro das agendas globais e dos Objetivos de Desenvolvimento Sustentável (World Health Organization, 2023). Esta realidade evidencia a necessidade de uma transformação paradigmática nos modelos de cuidados, atualmente ainda demasiado centrados nas doenças agudas, demonstrando fragilidades na resposta às complexidades inerentes às condições crónicas como a diabetes (International Diabetes Federation, 2021).

Apesar dos avanços promovidos pelas estratégias globais, com ênfase na prevenção e no diagnóstico precoce, estas medidas, isoladamente, têm-se revelado insuficientes para abordar de forma abrangente os desafios inerentes à gestão da diabetes (Hawash et al., 2024). Torna-se, assim, imprescindível implementar intervenções mais holísticas, que transcendam a pessoa diagnosticada, integrando dimensões familiares e contextos socioculturais que influenciam de forma determinante a gestão da diabetes (Pourhabibi et al., 2022; World Health Organization, 2022b).

Reconhecendo a complexidade da gestão da diabetes e a necessidade de abordagens que integrem os múltiplos fatores envolvidos, este projeto de investigação teve por base o Modelo de Intervenções Complexas da *Medical Research Council* (MRC) e os Modelos de Avaliação e Intervenção familiar de *Calgary* (CFAIM). O CFAIM permitiram destacar a família como uma unidade essencial de cuidados, explorando as suas dinâmicas, os papéis e as funções que influenciam diretamente a gestão da doença e os seus resultados (Wright & Leahey, 2013). Simultaneamente, o MRC ofereceu um enquadramento metodológico estruturado e flexível permitindo abordar os desafios das intervenções educativas no contexto da diabetes, desde a capacitação técnica dos profissionais até à inclusão de dimensões emocionais, sociais e culturais no cuidado (Bleijenberg et al., 2018; Craig et al., 2008).

Na fase do modelo da MRC, dedicada à identificação da evidência e à análise da prática corrente e do contexto atual, foram desenvolvidas duas revisões sistemáticas que fundamentam esta abordagem holística. A primeira centrou-se nas características psicométricas dos instrumentos utilizados para avaliar o envolvimento familiar no contexto da diabetes em adultos, enquanto a segunda revisão *umbrella* sintetizou a evidência sobre a efetividade das intervenções familiares na gestão da diabetes. Estas análises forneceram uma base sólida para compreender as lacunas existentes na prática atual, identificando áreas que necessitam de melhorias e inovações (Soares et al., 2023; Soares et al., 2024).

Deste modo, o presente projeto de investigação distingue-se ao propor uma intervenção centrada na díade - pessoa diagnosticada e a sua família - reconhecendo o papel central

dos enfermeiros enquanto facilitadores de mudança. Estes profissionais desempenham um papel indispensável na gestão da diabetes, transcendendo a prestação direta de cuidados para assumir a liderança e coordenação de intervenções educativas que promovam o empoderamento da díade e a melhoria da gestão da diabetes (Decreto-Lei nº 104/98, 2016) . Esta transição, de intervenções tradicionalmente focadas na melhoria de indicadores clínicos para abordagens mais equitativas e sustentáveis, que integram e valorizam as dinâmicas familiares como elementos essenciais para uma gestão efetiva da diabetes, reflete as exigências e desafios reais da gestão da diabetes, alinhando-se com as recomendações globais que promovem uma abordagem integrada e multidimensional (Pourhabibi et al., 2022; World Health Organization, 2022b).

Neste contexto, a prestação de cuidados de enfermagem desempenha um papel central neste processo, influenciando diretamente a qualidade dos cuidados ao adulto com diabetes e sua família, o seu acesso aos serviços de saúde e os resultados em saúde alcançados (Ordem dos Enfermeiros, 2011, 2015b; Ribeiro et al., 2017). A busca pela excelência nos cuidados e pela satisfação das pessoas cuidadas reforça a necessidade de investimento contínuo na formação e capacitação dos enfermeiros, com especial enfoque nos cuidados à família (Ordem dos Enfermeiros, 2001, 2005, 2011, 2015a).

Neste sentido, os Padrões de Qualidade dos Cuidados de Enfermagem (PQCE) emergem como referenciais de excelência, orientando a prática profissional e apoiando a tomada de decisões clínicas que respeitem as necessidades, crenças e valores da pessoa e da família (International Council of Nurses, 2022; Ordem dos Enfermeiros, 2012, 2015a). Estes padrões incentivam não apenas o desenvolvimento de cuidados personalizados e sensíveis especificidades de cada contexto, mas também a avaliação da sua qualidade, demonstrando o contributo específico dos enfermeiros na gestão de doenças crónicas como a diabetes (Ordem dos Enfermeiros, 2012).

A excelência no cuidado é crucial para garantir intervenções efetivas e sensíveis às necessidades da díade, contribuindo para melhores resultados na gestão da diabetes (Ordem dos Enfermeiros, 2012). Este investimento não só melhora o acesso das pessoas a profissionais altamente qualificados, como também potencia ganhos significativos em saúde, promovendo níveis elevados de satisfação entre as pessoas cuidadas e reforçando o impacto positivo da prática de enfermagem na gestão da diabetes (International Council of Nurses, 2022). Neste contexto, a satisfação das pessoas cuidadas destaca-se como um indicador essencial da qualidade dos cuidados de enfermagem, particularmente do adulto com diabetes (International Council of Nurses, 2022).

Medir e promover níveis elevados de satisfação não é apenas um objetivo, mas um componente central para melhorar os resultados em saúde (Ordem dos Enfermeiros, 2001; Ribeiro et al., 2017). Este indicador está intrinsecamente ligado à promoção da literacia, uma vez que pessoas mais satisfeitas têm maior probabilidade de se envolverem ativamente no seu processo de cuidados, reduzindo os efeitos adversos de uma literacia limitada (Augusto et al., 2023).

Assim, os enfermeiros devem procurar continuamente alinhar as suas práticas com os mais elevados padrões de qualidade, assegurando que a voz das pessoas é ouvida e valorizada (Nunes, 2023). A satisfação das pessoas, que cruza perceções, expectativas e necessidades, é uma ferramenta valiosa para monitorizar a qualidade dos cuidados e identificar áreas de melhoria na gestão da diabetes (Melo, 2023). Nesse sentido, a personalização dos cuidados, frequentemente referida como *"tailored care"*, é uma estratégia que não apenas melhora os resultados clínicos, mas também fortalece a relação terapêutica, assegurando que as intervenções respeitem as preferências, expectativas e contextos de vida das pessoas cuidadas (International Council of Nurses, 2022).

Além de refletir a qualidade técnica dos cuidados, a busca por elevados níveis de satisfação evidencia a capacidade dos enfermeiros de escutar ativamente, compreender e responder às preocupações das pessoas com diabetes sob os seus cuidados, particularmente em contextos de maior vulnerabilidade (Ordem dos Enfermeiros, 2001, 2015b, 2023). A comunicação entre os enfermeiros, pessoas diagnosticadas e suas famílias emerge assim como um elemento central na gestão da diabetes (Alexandre et al., 2021). Relações baseadas na descoberta de sentidos entre quem cuida e é cuidado, empatia, respeito mútuo e colaboração não só promovem confiança, mas também têm um impacto direto na adesão ao regime terapêutico, um fator essencial para alcançar os objetivos de tratamento e prevenir complicações associadas à doença. De forma complementar, este processo contribui para a melhoria da qualidade de vida das pessoas com diabetes e suas famílias, ao mesmo tempo que promove o desenvolvimento profissional do enfermeiro, ampliando as suas competências no cuidado à família e fortalecendo a sua capacidade de intervenção em contextos complexos de saúde. Adicionalmente, uma comunicação efetiva facilita o esclarecimento de dúvidas, reduz a ansiedade e estimula a parceria efetiva das pessoas e famílias no seu processo de cuidados, transformando a interação com o enfermeiro num momento de capacitação e promoção da autonomia (Alexandre et al., 2021).

Com base nestas premissas, este projeto de investigação, alinhado com as fases do Modelo do MRC, em particular a fase de “Determinar Necessidades”, expande o foco tradicional da gestão da diabetes para incluir não apenas o adulto diagnosticado, mas

também os seus familiares. Assim, foi desenvolvido um estudo em duas fases, refletido num artigo que integrou uma scoping review e a análise qualitativa de um grupo focal realizados com a díade (adulto com diabetes e família), bem como reuniões com profissionais de saúde que cuidam diariamente desta população. Estas etapas permitiram identificar as barreiras locais à implementação de intervenções familiares e recolher contributos essenciais para o desenvolvimento do programa *Juntos com a Família + Capazes* e do seu guião, assegurando que este se adapta às realidades específicas dos contextos e das necessidades sentidas e expressas da população-alvo (Soares et al., 2025).

Na fase de Modelação do Processo e Resultados Esperados, partindo das evidências identificadas na fase anterior, foram concretizados dois marcos fundamentais deste projeto: a validação cultural e linguística do instrumento *Family and Friend Involvement in Adults' Diabetes* (FIAD) para a população portuguesa e o desenvolvimento e validação conceptual do programa de intervenção Juntos com a Família + Capazes.

A adaptação e validação do FIAD-PT constituiu uma etapa central na consolidação de ferramentas específicas para avaliar as duas dimensões (suporte e de obstrução) do envolvimento familiar na gestão da diabetes. Além disso, o FIAD-PT será utilizado para avaliar a efetividade do programa de intervenção *Juntos com a Família + Capazes*, assegurando que os resultados obtidos reflitam o impacto real do envolvimento familiar na gestão da diabetes e nos resultados em saúde obtidos (American Diabetes Association, 2022; International Diabetes Federation, 2021; Mayberry et al., 2019).

Paralelamente, o programa *Juntos com a Família + Capazes* foi desenvolvido com base na evidência científica mais recente e num processo de validação conceptual que envolveu grupos focais com a díade e com peritos multidisciplinares. Este processo incluiu a experiência acumulada da equipa de investigação, na prática clínica e na investigação, assim como profissionais de saúde com experiência direta no cuidado à pessoa com diabetes e às suas famílias, assim como garantindo que o programa reflete as necessidades reais e os desafios encontrados na prática clínica. A abordagem adotada visou integrar as dinâmicas familiares, promovendo o empoderamento da pessoa diagnosticada e da sua família enquanto unidade de cuidado (American Diabetes Association, 2022; Shajani & Snell, 2019).

A fase de modelação resultou também na elaboração do guião de implementação do programa *Juntos com a Família + Capazes*, direcionado aos profissionais de saúde, assegurando que a intervenção seja conduzida de forma sistemática e alinhada com os objetivos estabelecidos. Este documento reflete o reconhecimento de que a gestão da

diabetes é um processo colaborativo, que requer uma partilha de responsabilidades entre a pessoa diagnosticada, a sua família e os profissionais de saúde. Pese embora o guião estabeleça diretrizes claras, foi cuidadosamente elaborado para permitir que os profissionais personalizem as intervenções, ajustando-as às particularidades e necessidades especificas das pessoas diagnosticadas, das suas famílias e dos contextos socioeconómicos e culturais em que estão inseridas, previamente identificadas através de uma avaliação cuidadosa e sistemática (American Diabetes Association, 2022; Shajani & Snell, 2019).

A implementação do programa *Juntos com a Família + Capazes* em contextos clínicos reais constitui uma oportunidade ímpar para transformar a gestão da diabetes. Este programa equilibra a personalização das intervenções com uma abordagem sistemática, promovendo o empoderamento da díade, através do aumento da literacia em saúde até à sua dimensão crítica, dotando os participantes de ferramentas práticas para decisões informadas e uma gestão sustentável da doença (Nutbeam & Lloyd, 2021; Sørensen, 2022). A integração deste programa no plano individual de cuidados do adulto com diabetes, com ênfase na sua componente educativa, promove a capacitação da díade para a reconstrução dos seus projetos de saúde e o desenvolvimento da autonomia (American Diabetes Association, 2022; American Diabetes Association, 2023).

Esta abordagem requer um trabalho colaborativo e multidisciplinar, no qual se deve fortalecer a articulação entre as UCC, USF e UCSP. Este processo deve assim, contemplar tanto as especificidades clínicas quanto os fatores sistémicos que influenciam a gestão da diabetes, como a acessibilidade aos serviços de saúde, os custos associados às intervenções e as barreiras locais à sua implementação (Kuratli et al., 2023; Mondesir et al., 2019; Yao et al., 2021). O uso de contratos de gestão, desenvolvidos em colaboração com a díade, juntamente com a definição de objetivos SMART proporciona um acompanhamento estruturado, efetivo e adaptado a cada contexto (Bosch-Capblanch et al., 2007; Gallagher et al., 2022; Magtoto, 2023).

Apesar dos avanços propostos pelo programa, é inegável que os enfermeiros continuam a enfrentar desafios na prática clínica, particularmente relacionados com a promoção adesão ao regime terapêutico (International Diabetes Federation, 2021). Estudos indicam que apenas metade das intervenções educativas implementadas geram resultados positivos (Kuratli et al., 2023). Embora o insucesso dessas intervenções seja frequentemente atribuído a fatores intrínsecos à díade, é crucial que os profissionais de saúde reconheçam o seu papel no sucesso das intervenções e na obtenção de ganhos em saúde, investindo na sua formação contínua (American Diabetes Association, 2023; Kuratli et al., 2023; Powers et al., 2020a).

A formação contínua dos enfermeiros é essencial para desenvolver competências técnicas, habilidades psico-emocionais e comunicacionais, promovendo o desenvolvimento de técnicas como a escuta ativa e a interação bidirecional, que são fundamentais para a adesão terapêutica e a sustentabilidade dos resultados em saúde (American Diabetes Association, 2023; Kuratli et al., 2023; Powers et al., 2020a). Além disso, é necessário que os profissionais dediquem tempo suficiente para compreender e responder às preocupações das pessoas diagnosticadas (Alexandre et al., 2021; Lee, 2018; Pourhabibi et al., 2022). A falta de tempo, frequentemente referido pelas pessoas, é uma barreira significativa à adesão terapêutica, levando a perceções de que a informação transmitida é confusa ou inadequada às suas necessidades específicas pouco ajustada às suas necessidades específicas (American Diabetes Association, 2023; Kuratli et al., 2023; Lee, 2018; Powers et al., 2020a).

A gestão efetiva da diabetes exige um compromisso conjunto entre profissionais de saúde, decisores políticos e a sociedade, com vista à implementação de políticas públicas robustas que promovam o acesso universal a cuidados de saúde e o empoderamento das pessoas diagnosticadas e das suas famílias (Elsayed et al., 2023). Alinhadas com os princípios da *Carta de Ottawa*, estas políticas devem priorizar a equidade, fomentar a autonomia e reduzir as barreiras relacionadas com os custos das intervenções e a acessibilidade aos serviços (World Health Organization, 1986).

Neste contexto, pretende-se que o programa *Juntos com a Família + Capazes***,** com o apoio de instrumentos como o FIAD-PT para avaliar a eficácia das intervenções, se constitua numa abordagem inovadora e robusta. A sua implementação tem o potencial de melhorar os resultados em saúde, reduzir complicações associadas à diabetes e reforçar o papel essencial da família na gestão da doença, promovendo uma qualidade de vida superior para todas as partes envolvidas.

CONCLUSÃO

A diabetes mellitus, pela sua elevada prevalência e impacto global, continua a representar um desafio significativo de saúde pública, exigindo abordagens inovadoras e integradas para a sua gestão efetiva (International Diabetes Federation, 2021). Esta tese procurou dar resposta a essa problemática através do desenvolvimento e validação conceptual de uma intervenção psicoeducativa de enfermagem inovadora, centrada na díade - pessoa diagnosticada e família - sustentada em evidências científicas e abordagens multidisciplinares. O programa *Juntos com a Família + Capazes* representa uma transição essencial para um modelo de cuidados colaborativo e integrado, no qual o envolvimento ativo da família se revela um elemento determinante para a adesão terapêutica e a sustentabilidade dos comportamentos de autocuidado.

Ao longo deste trabalho, evidenciou-se a importância da literacia em saúde e da capacitação do adulto com diabetes e da sua família, reforçando o papel central do empoderamento e a personalização dos cuidados na obtenção de melhores resultados em saúde. A integração da família na gestão da diabetes demonstrou-se fundamental para fortalecer o suporte emocional e instrumental, promovendo a adesão a planos terapêuticos e otimizando os resultados clínicos e psicossociais.

A estruturação do programa teve por base três modelos teóricos robustos, nomeadamente os Modelos de Avaliação e Intervenção Familiar de *Calgary* e o Modelo de Intervenções Complexas do *Medical Research Council*, garantindo um enquadramento científico sólido para a compreensão das dinâmicas familiares e para o desenvolvimento de uma intervenção estruturada e ajustada às necessidades da díade. Esta abordagem assegurou que o programa fosse construído de forma sistemática, adaptável e cientificamente sustentada, promovendo um impacto positivo na gestão da diabetes e no bem-estar das pessoas diagnosticadas e das suas famílias.

Paralelamente, esta tese reconhece o papel central dos enfermeiros enquanto facilitadores da mudança, promovendo cuidados baseados na escuta ativa, na comunicação empática e na adaptação das intervenções às especificidades individuais e familiares. A proximidade dos enfermeiros à pessoa diagnosticada e à sua família permite um acompanhamento contínuo e personalizado, garantindo que as necessidades emergentes ao longo dos diferentes estadios da doença sejam identificadas e integradas nos planos de cuidados com a mobilização dos recursos necessários para a sua superação.

Embora a transição de um modelo de cuidados tradicional e prescritor para um papel mais ativo na facilitação da gestão da doença seja inevitável e necessária, constitui, simultaneamente, uma oportunidade para os enfermeiros afirmarem o contributo da sua prática na gestão da diabetes e nos resultados em saúde**.** No entanto, para que esta

mudança se traduza em intervenções mais efetivas e sustentáveis, torna-se imprescindível investir na formação contínua dos profissionais e na revisão dos currículos da formação de base em enfermagem**,** garantindo que o ensino da enfermagem familiar e da gestão da diabetes incorpore abordagens inovadoras e sustentadas na evidência científica.

A implementação do programa desenvolvido reforça, ainda, a necessidade de políticas públicas que assegurem equidade no acesso aos recursos de saúde e aos serviços de qualidade, garantindo que todas as pessoas com diabetes e suas famílias possam beneficiar de intervenções efetivas e ajustadas aos seus contextos.

A criação de estratégias para a expansão do programa *Juntos com a Família + Capazes* a diferentes populações e cenários culturais será crucial para validar a sua aplicabilidade e sustentabilidade a longo prazo.

No futuro, será essencial dar continuidade à avaliação da eficácia e do impacto do programa em diferentes contextos de saúde**,** explorando o seu contributo na redução das complicações associadas à diabetes e na melhoria da qualidade de vida da díade. Estudos longitudinais e ensaios clínicos poderão fornecer dados adicionais sobre a sua efetividade e orientar novas adaptações e melhorias. Além disso, a integração desta intervenção nos planos individuais de cuidados, articulada com equipa multidisciplinares e redes de apoio comunitário**,** poderá amplificar os seus efeitos positivos e consolidar uma abordagem verdadeiramente centrada na pessoa e na família.

Desta forma, esta tese não só contribui para o avanço do conhecimento na área da gestão da diabetes**,** como também reforça a necessidade de intervenções estruturadas, equitativas e inclusivas que promovam a saúde, o bem-estar e a qualidade de vida das pessoas diagnosticadas e das suas famílias. Ao propor um modelo sustentado na excelência dos cuidados, na colaboração interprofissional e no reconhecimento da família como unidade central de apoio**,** este trabalho alicerça um caminho promissor para a melhoria contínua da gestão da diabetes e das suas complexidades associadas.

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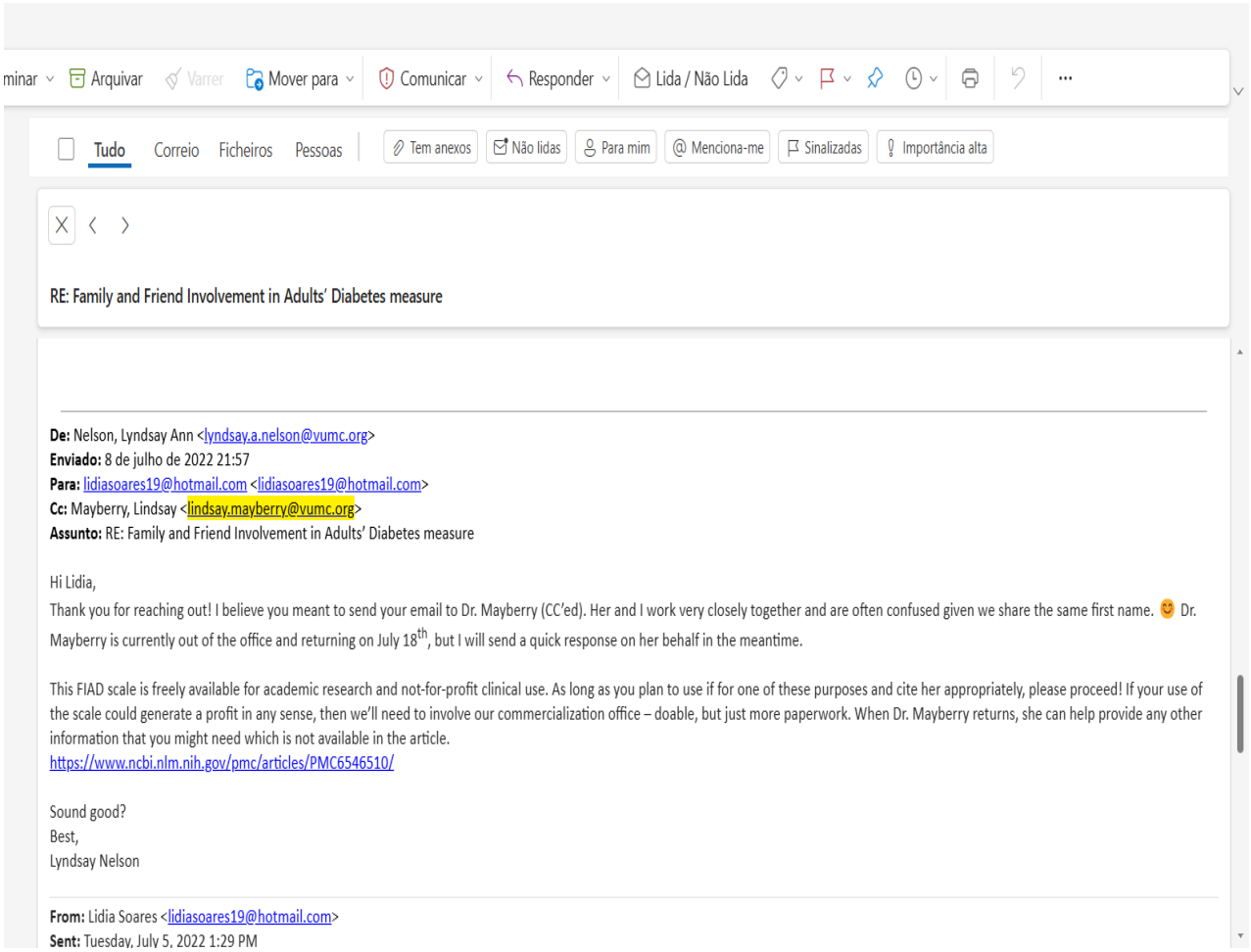
ANEXOS

Anexo I: Autorização das autoras originais do Instrumento *Family And Friend Involvement In Adults' Diabetes (FIAD)*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Tem anexos
Não lidas
Para mim
Menciona-me
Sinalizadas
Importância alta
RE: Family and Friend Involvement in Adults' Diabetes measure
De: Nelson, Lyndsay Ann <lyndsay.a.nelson@vumc.org>
Enviado: 8 de julho de 2022 21:57
Para: lidiasoares19@hotmail.com <lidiasoares19@hotmail.com>
Cc: Mayberry, Lindsay <lindsay.mayberry@vumc.org>
Assunto: RE: Family and Friend Involvement in Adults' Diabetes measure
Hi Lidia,
Thank you for reaching out! I believe you meant to send your email to Dr. Mayberry (CC'ed). Her and I work very closely together and are often confused given we share the same first name. Dr. Mayberry is currently out of the office and returning on July 18th, but I will send a quick response on her behalf in the meantime.
This FIAD scale is freely available for academic research and not-for-profit clinical use. As long as you plan to use if for one of these purposes and cite her appropriately, please proceed! If your use of the scale could generate a profit in any sense, then we'll need to involve our commercialization office – doable, but just more paperwork. When Dr. Mayberry returns, she can help provide any other information that you might need which is not available in the article.
https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6546510/
Sound good?
Best,
Lyndsay Nelson
From: Lidia Soares <lidiasoares19@hotmail.com>
Sent: Tuesday, July 5, 2022 1:29 PM

Anexo II: Autorização da Comissão de Ética para o Estudo de Adaptação e Validação do Instrumento *Family And Friend Involvement In Adults' Diabetes (FIAD)*

Comissão de Ética para a Saúde (CES)

Data de Entrada no Secretariado da CES: Nº 01 de 17/01/2023 **Assunto:** Estudo 2 - "Adaptação e Validação do Instrumento (FIAD) de Avaliação Familiar para a população portuguesa"	Solicitado pelo Conselho de Administração Em nome do(s) investigador(es): Vânia Lídia da Silva Soares 3º Ano do Doutoramento em Ciências de Enfermagem no Instituto de Ciências Biomédicas Abel Salazar da Universidade do Porto (ICBAS-UP)

1. A(s) questão(ões) colocada(s)

Solicita autorização para a realização de um estudo de investigação "Adaptação e validação do Instrumento FIAD - Participação de familiares e amigos na Gestão da Diabetes em adultos para a população Portuguesa". Este estudo é descrito como **estudo dois** e integra o projeto de investigação, intitulado "Literacia em Saúde da Pessoa com Diabetes e Família: Efetividade de uma Intervenção Psicoeducativa de Enfermagem", que foi aprovado pelo ICBAS, no âmbito do Doutoramento em Ciências de Enfermagem. O Projeto de Investigação integra quatro estudos, que embora distintos, se complementam entre si para dar resposta à questão de Investigação: ***Quais os ganhos em saúde para a pessoa com Diabetes Mellitus tipo 2 e família decorrentes do envolvimento ativo e intencional da família na gestão da DM tipo 2?"***

Trata-se de um estudo quantitativo que pretende validar e adaptar (linguisticamente e culturalmente) para a população Portuguesa o instrumento FIAD, que permite aos profissionais de saúde reconhecer o ambiente o envolvimento familiar da pessoa diagnosticada com Diabetes, através da recolha de informação por preenchimento de um questionário de caraterização sociodemográfico e a aplicação do Instrumento FIAD, por autopreenchimento ou com recurso à entrevista com uma duração máxima de aproximadamente 15 minutos, após preenchimento do Consentimento informado. O instrumento FIAD permite identificar os comportamentos de suporte e não suporte da família e amigos na gestão diária da Diabetes, o que se revela de extrema importância para o desenvolvimento e avaliação das intervenções com a pessoa diagnosticada com Diabetes e família. Os dados recolhidos serão analisados por procedimentos estatísticos inerentes à validação de uma escala, designadamente a análise fatorial.

Para o desenvolvimento deste estudo (estudo 2), é definida como população alvo, adultos com diabetes que frequentem as consultas da diabetes nas Unidades de Saúde Familiares Gil Eanes, Terra do Nóbrega, Vale do Lima, Monção, Darque e Arquis Nova, das Unidades de Saúde de Cuidados Personalizados de Monção e Valença e da Consulta Externa de Endocrinologia, pertencentes à ULSAM, EPE.

São critérios de inclusão pessoas com diagnóstico de Diabetes: Idade igual ou superior a 18 anos; falar, escrever e compreender a língua portuguesa; são critérios de exclusão: pessoa grávida com diabetes e pessoas com alterações mentais e psiquiátricas.

A recolha, processamento e uso dos dados recolhidos será sempre realizado de forma confidencial e apenas para os efeitos do presente estudo.

Está garantido o anonimato dos participantes e o contacto com estes será realizado em ambiente de privacidade.
Os dados recolhidos serão destruídos um ano após a conclusão do estudo.

2. Fundamentação

A Diabetes Mellitus (DM), apresenta uma prevalência crescente a nível mundial. O seu impacto aos vários níveis, pessoal, familiar, socioeconómico e nos sistemas de saúde, torna emergente a necessidade de desenvolvimento de novas abordagens de educação terapêutica com a pessoa diagnosticada, nas quais se assume como fulcral o envolvimento qualificado e intencional da família.
A inclusão da família, destacada na literatura como determinante para o sucesso das abordagens educativas, promove a autogestão da DM e ganhos em Saúde, como consequente redução das comorbilidades e complicações geralmente associadas à DM.
Neste contexto, surge a pretensão por parte da investigadora, de desenvolver um projeto de investigação que permita avaliar a efetividade do envolvimento da pessoa com DM e famílias em programa psicoeducativo, numa lógica de cocriação, orientado para ganhos em saúde, nomeadamente ao nível do conhecimento específico da doença, autoeficácia percebida, qualidade de vida relacionada com a saúde e indicadores clínicos.

3. Conclusão/parecer

É imperativo que a abordagem ao doente para eventual participação no estudo, seja sempre feita pela equipa cuidadora do doente e nunca diretamente pelo investigador.
Após a conclusão do projeto o investigador deverá comunicar à CES o seu término, bem como enviar cópia do relatório realizado.
O estudo solicitado cumpre os requisitos exigidos pela CES da ULSAM, no Mod. Q741, e Mod,Q 755 pelo que nada há a opor à autorização requerida.

Nota: Referências bibliográficas:
São apresentadas dezassete referências bibliográficas.

Relator(es)	Ângela Sampaio
Ratificado em reunião do dia	23-02-2023
Enviado parecer: ___/___/_____	

23/02/2023 O Presidente da CES _____

DR. CARLOS RIBEIRO
Presidente da CES

Rosário Barros
Enfermeira Diretora

Anexo III: Consentimento Informado para os Participantes do Estudo de Adaptação e Validação do Instrumento *Family And Friend Involvement In Adults' Diabetes (FIAD)*

CONSENTIMENTO INFORMADO, LIVRE E ESCLARECIDO PARA PARTICIPAÇÃO EM PROJETOS DE DOCÊNCIA E/OU INVESTIGAÇÃO

de acordo com a Declaração de Helsínquia[1] e a Convenção de Oviedo[2]

Por favor, leia com atenção a seguinte informação. Se achar que algo está incorreto ou que não está claro, não hesite em solicitar mais informações. Se concorda com a proposta que lhe foi feita, queira assinar este documento.

Título do estudo: Adaptação e validação do instrumento FIAD (Envolvimento de familiares e amigos na gestão da Diabetes em Adultos) para a população Portuguesa.

Enquadramento: O estudo de investigação que se pretende desenvolver é descrito como **estudo dois** e integra o projeto de investigação, intitulado "Literacia em Saúde da Pessoa com Diabetes e Família: Efetividade de uma Intervenção Psicoeducativa de Enfermagem". Este encontra-se a ser realizado pela enfermeira Vânia Lídia da Silva Soares, no âmbito do Doutoramento em Ciências de Enfermagem do Instituto de Ciências Biomédicas Abel Salazar da Universidade do Porto (ICBAS-UP), sob orientação do Professor Doutor Carlos Alberto Sequeira, da Professora Doutora Maria do Céu Barbieri-Figueiredo e da Professora Doutora Carminda Morais.

Explicação do estudo: Este estudo será realizado com adultos com diabetes que frequentem as consultas da diabetes nas suas unidades funcionais ou hospitais. Serão preenchidos dois instrumentos (instrumento a validar e questionário de caracterização sociodemográfica) através de uma entrevista realizada pelo investigador principal, ou através do autopreenchimento, com uma duração máxima de aproximadamente 15 minutos. Para a realização do reteste a pessoa será contactada telefonicamente (telefone da Unidade Funcional), no período compreendido entre 15 e 30 dias após o preenchimento do primeiro questionário.

Assegura-se que os dados recolhidos serão destruídos um ano após a conclusão do estudo.

Condições e financiamento: A sua participação neste estudo é voluntária, sem custos associados, salientando-se que não existem compensações por despesas de deslocação ou outros incómodos. Poderá interromper a sua participação a qualquer momento, sem quaisquer consequências ou prejuízos futuros, nomeadamente prejuízos assistenciais. Este estudo mereceu, após ter sido submetido a análise, um Parecer Favorável da Comissão de Ética da ULSAM, EPE.

Confidencialidade e anonimato: A recolha, processamento e uso dos dados recolhidos será sempre realizado de forma confidencial e apenas para os efeitos do presente estudo. O anonimato dos participantes será garantido e a sua identificação nunca será tornada pública. O contacto com os participantes deste estudo será feito sempre em ambiente de privacidade.

Agradecimentos e identificação do/a investigador/a e da pessoa que pede o consentimento, se for diferente: Em meu nome - Vânia Lídia da Silva Soares, Enfermeira e Doutoranda em Ciências

[1] http://portal.arsnorte.min-saude.pt/portal/page/portal/ARSNorte/Comiss%C3%A3o%20de%20%C3%89tica/Ficheiros/Declaracao_Helsinquia_2008.pdf

[2] http://dre.pt/pdf1sdip/2001/01/002A00/00140036.pdf

de Enfermagem do ICBAS-UP, do Professor Doutor Carlos Alberto Sequeira, da Professora Doutora Maria do Céu Barbieri-Figueiredo e da Professora Doutora Carminda Morais (Orientadores) - agradeço antecipadamente a atenção por si disponibilizada a este estudo. Qualquer dúvida poderá ser esclarecida através do email: **lidiasoares19@hotmail.com**.

Assinatura(s):

……..
Doutoranda Vânia Lídia da Silva Soares

……..
Professor Doutor Carlos Alberto Sequeira

……..
Professora Doutora Maria do Céu Barbieri-Figueiredo

……..
Professora Doutora Carminda Morais

Declaro ter lido e compreendido este documento, bem como as informações verbais que me foram fornecidas pela/s pessoas/s que acima assina/m e que considero suficientes. Foi-me garantida a possibilidade de, em qualquer altura, recusar participar neste estudo sem qualquer tipo de consequências. Desta forma, aceito participar neste estudo e permito a utilização dos dados que de forma voluntária forneço, confiando em que apenas serão utilizados para esta investigação e nas garantias de confidencialidade e anonimato que me são dadas pelo/a investigador/a.

Nome: _____

Assinatura: Data: __ /__ /_____

ESTE DOCUMENTO, COMPOSTO DE 2 PÁGINA/S, É FEITO EM DUPLICADO:
UMA VIA PARA O/A INVESTIGADOR/A, OUTRA PARA A PESSOA QUE CONSENTE

Anexo IV: Autorização da Comissão de Ética para o Estudo de Validação Conceptual do Programa *Juntos com a Família + Capazes*

Comissão de Ética para a Saúde (CES)

Data de Entrada no Secretariado da CES: Nº 09 de 20/02/2024	Solicitado pelo Conselho de Administração
Assunto:	Em nome do(s) investigador(es):
Autorização para realizar um trabalho de investigação intitulado "Literacia em Saúde da Pessoa com Diabetes e Família: Efetividade de uma intervenção psicoeducativa de Enfermagem"	Vânia Lídia da Silva Soares - Doutoranda em Ciências de Enfermagem da Universidade do Porto, ICBAS

1. A(s) questão(ões) colocada(s)

É pedida autorização para realizar um trabalho de investigação intitulado "Literacia em Saúde da Pessoa com Diabetes e Família: Efetividade de uma intervenção psicoeducativa de Enfermagem". São orientadores os professores doutores Carlos Alberto da Cruz Sequeira, Maria do Céu Barbieri Figueiredo e Carminda Soares Morais.
Pretende-se desenvolver um projeto de investigação que permita avaliar a efetividade do envolvimento da pessoa com Diabetes mellitus e famílias em programa psicoeducativo, numa lógica de cocriação, orientado para ganhos em saúde, nomeadamente ao nível do conhecimento específico da doença, autoeficácia percebida, qualidade de vida relacionada com a saúde e indicadores clínicos.
O presente trabalho é o estudo 3 de um trabalho de investigação. O projeto de investigação integra quatro estudos, que embora distintos se complementam entre si. O estudo 1 refere-se a uma revisão sistemática da literatura dos instrumentos de avaliação da família utilizados no contexto da Diabetes e foi desenvolvido de acordo com a metodologia proposta pelo Joanna Briggs Institute. O estudo 2, tem como objetivo adaptar e validar para a População Portuguesa o instrumento FIAD (Envolvimento de Familiares e Amigos na gestão da Diabetes em Adultos), o qual foi identificado no estudo 1. No estudo 3 pretende-se desenvolver uma intervenção psicoeducativa centrada na família. O estudo 4, tratando-se de um ensaio clínico randomizado, objetiva a avaliação da efetividade da intervenção psicoeducativa.

Metodologia Estudo
Metodologia qualitativa, designadamente através da realização de um grupo focal com o grupo de peritos, mais especificamente as pessoas diagnosticadas com Diabetes tipo 2 e suas famílias.
Objetivos
- Desenvolvimento de uma intervenção psicoeducativa com as pessoas com Diabetes tipo 2 e família;
- Validação conceptual da intervenção com recurso a grupos focais com as pessoas diagnosticadas e família.

População Alvo

Pessoas com Diabetes tipo 2 e famílias, da Região do Alto Minho, que frequentem as consultas da Unidade de Saúde Familiar Gil Eanes pertencente à ULSAM, EPE.

A amostra será determinada a partir de uma técnica de amostragem por não probabilística por conveniência. Pretende-se que o número de participantes seja no mínimo de 6.

Partindo do interesse e disponibilidade da pessoa para participar neste estudo de investigação, definem-se os seguintes critérios para a pessoa diagnosticada:

- Pessoas com diagnóstico de Diabetes tipo 2;
- Idade igual ou superior a 18 anos;
- Falar, escrever e compreender a língua Portuguesa.

Neste estudo adotou-se uma definição mais abrangente de família, que não se encontra restrita pela consanguinidade.

Assim, independentemente de coabitarem ou não na mesma residência os critérios para a inclusão do familiar incluem:

-Pessoa que dá suporte (instrumental, económico, emocional entre outros) à pessoa diagnosticada com Diabetes na gestão da sua doença;
-Idade igual ou superior a 18 anos;
-Falar, escrever e compreender a língua Portuguesa.

Como critérios de exclusão definem-se:

-Pessoa grávida com Diabetes;
-Pessoas com alterações mentais e psiquiátricas.

Aos participantes serão explicitados os objetivos e natureza do estudo e o âmbito da participação e assinando um consentimento informado. Tratando-se de uma participação voluntária será assegurada a possibilidade dos participantes poderem interromper a sua participação a qualquer momento, sem quaisquer consequências ou prejuízos futuros, nomeadamente prejuízos assistenciais.

Local de Realização:

Unidade de Saúde Familiar Gil Eanes.

Autorização

Foi autorizada a realização do estudo pela coordenadora da USF.

2. Fundamentação

A DM é identificada como uma das principais causas evitáveis de morbilidade, incapacidade e morte prematura. Reconhecendo como fulcral o apoio familiar para o sucesso da abordagens desenvolvidas no âmbito da DM tipo 2 e em alinhamento com as recomendações internacionais, este plano de estudos representa uma oportunidade de identificar novas estratégias de gestão da DM tipo 2, que se pretendem mais efetivas, com criação de valor e ganhos em saúde para a pessoa diagnosticada, a família e a comunidade, designadamente ao nível do aumento do conhecimento específico, autoeficácia, qualidade de vida, adesão ao regime terapêutico e dos vários indicadores clínicos.

Urge empoderar não apenas as pessoas com DM, mas as suas famílias, envolvendo-as de forma ativa e intencional nos desafios comportamentais que a doença exige, visando a prevenção, redução das complicações e mortalidade que lhe estão associadas.

Neste alinhamento, com este estudo objetiva-se o desenvolvimento de uma intervenção psicoeducativa de Enfermagem através de uma parceria efetiva entre os profissionais e peritos da área e as pessoas diagnosticadas e sua família.

3. Conclusão/parecer

Não se afigura serem desrespeitadas as exigências éticas e legais para o fim em vista do estudo, pelo que deve ser dado parecer positivo ao solicitado.

Nota: Referências bibliográficas:

Foram apresentadas 18 referências

Relator(es)	Nelson Rodrigues
Ratificado em reunião do dia	26/03/2024
Enviado parecer: ___/___/_____	

26/03/2024 O Presidente da CES _____

DR. CARLOS RIBEIRO
Presidente da CES

Anexo VI: Consentimento Informado e Guião do Grupo de Discussão Focal

Validação do programa "Juntos com a família + Capazes" para implementar com a pessoa diagnosticada com Diabetes Mellitus tipo 2 e família

Termo de consentimento informado

Obrigada por participar neste estudo. Por favor leia com atenção a informação abaixo.

Este estudo tem como objetivo principal o desenvolvimento de uma intervenção psicoeducativa com o adulto diagnosticado com Diabetes tipo 2 e família, que se intitula "Juntos com a família + Capazes".

Integra-se no trabalho de investigação desenvolvido no âmbito da tese de doutoramento em Ciências de Enfermagem do Instituto de Ciências Biomédicas Abel Salazar (ICBAS) da estudante Lídia Soares, sob orientação do Professor Doutor Carlos Alberto Sequeira, da Professora Doutora Maria do Céu Barbieri-Figueiredo e da Professora Doutora Carminda Morais.

O programa "Juntos família + Capazes" foi desenvolvido através da revisão da literatura, designadamente uma revisão sistemática e uma revisão umbrela centradas na efetividade das intervenções desenvolvidas com adultos com Diabetes e suas famílias.

Com este estudo pretende-se validar conceptualmente o programa "Juntos com a família + Capazes".

A sua participação neste estudo é voluntária e confidencial. No caso de não aceitar participar ou decidir sair do estudo no seu decurso, essa decisão será inteiramente respeitada.

Os dados serão recolhidos através de discussão de grupo focal online, realizada através da plataforma "Zoom". Os participantes serão profissionais de saúde, a pessoa diagnosticada com Diabetes, familiares e os orientadores do estudo.

A sessão será gravada em vídeo e poderão ser tiradas notas. As gravações serão utilizadas apenas para a transcrição e exclusivamente pela equipa de investigação, sendo que as mesmas serão destruídas quando o trabalho de investigação estiver terminado. As gravações não serão partilhadas com terceiros. A identificação dos/as participantes não constará das transcrições ou publicações que vierem a ser produzidas no âmbito deste estudo.

ESTE DOCUMENTO É COMPOSTO DE 2 PÁGINAS

Declaração de consentimento informado

Eu, _____ (nome completo), declaro que tomei conhecimento de todas as explicações acerca do pedido que me é feito, compreendi a informação sobre o estudo anteriormente referido, tendo-me sido disponibilizado tempo para refletir sobre a participação, colocar as minhas dúvidas e ficar esclarecido/a.

- Consinto participar no grupo de discussão focal, autorizando que os dados recolhidos sejam usados na investigação, incluindo a disseminação científica
- Consinto a gravação em vídeo

Porto, _____ de abril de 2024

Assinatura do/a participante:
_____
Assinatura da investigadora:
_____

Contactos:
E-mail: lidiasoares19@hotmail.com
Telemóvel: 936385371

PLANO ORIENTADOR DE SESSÕES DO GRUPO FOCAL

Itens	Papel do Moderador
Introdução	Agradecer aos participantes a disponibilidade de participação; Propor a apresentação dos participantes.
Legitimação dos Elementos do Grupo Focal	Solicitar autorização para gravação; Assegurar a não divulgação da gravação, e que apenas servirá para análise de informação; Assegurar o anonimato das opiniões; Destacar a importância da participação de todos no debate.
Desenvolvimento	Apresentar a finalidade e objetivo do programa "Juntos família + Capazes"; Contextualizar de forma breve as fases do desenvolvimento do programa; Expor os objetivos específicos: • Conhecer a perceções dos participantes relativamente à **estrutura programa**; • Conhecer a perceções dos participantes relativamente aos **conteúdos do programa**; • Conhecer a perceções dos participantes relativamente à **metodologia**; Propor a avaliação da sessão pelos presentes.
Conclusão	Agradecer a disponibilidade de colaboração; Dar garantia do cumprimento dos princípios éticos, relativamente à confidencialidade da informação; Informar que os resultados não serão acessíveis após o término do trabalho.

Objetivo 1: Conhecer quais são as caraterísticas definidoras de um programa de intervenção psicoeducativa de Enfermagem com as pessoas com Diabetes tipo 2 e família relativamente à sua estrutura

Objetivos específicos	Questões – Chave	Tópicos de questões a explorar no debate
Conhecer as perceções dos participantes relativamente à estrutura do programa	Qual a duração adequada do programa? Qual a duração adequada das sessões? Qual duração adequada dos contactos telefónicos? Qual a duração adequada dos grupos de WhatsApp e Facebook? Quantas sessões deverão ser incluídas no programa? Qual deverá ser a periocidade das sessões? Quem devem ser os participantes das diferentes sessões?	- Qual considera ser a duração adequada de um programa? - Qual considera ser a duração adequada das sessões? - Considera que a duração das sessões deve variar de acordo com a metodologia adotada (presencial ou via zoom)? - Qual considera ser a duração adequada dos contactos telefónicos a realizar durante a intervenção? E do *follow up*? - Qual considera ser a duração adequada dos contactos telefónicos a realizar durante a intervenção? - Qual considera que deverá ser o período que o recurso ao WhatsApp e Facebook estará disponível? - Quantas sessões considera que devem ser incluídas no programa? - Quantos contactos telefónicos considera que devem ser incluídas no programa? E no *follow-up*? - Qual considera que deverá ser o período de tempo entre sessões? - Qual considera que deverá ser o período de tempo entre os contactos telefónicos incluídos no programa? E no *follow-up*? - Quem deverão ser os participantes das sessões presenciais? - Quem deverão ser os participantes das sessões via zoom?

Objetivo 2: Conhecer quais são as caraterísticas definidoras de um programa de intervenção psicoeducativa de Enfermagem com as pessoas com Diabetes tipo 2 e família relativamente ao seu conteúdo

Objetivos específicos	Questões – Chave	Tópicos de questões a explorar no debate
Conhecer as perceções dos participantes relativamente aos conteúdos do programa	Quais os conteúdos que devem ser abordados num programa desenvolvido com as pessoas com Diabetes tipo 2 e família	- Quais conteúdos considera que devem ser abordados num programa de intervenção psicoeducativa? - Concorda com os conteúdos abordados ao longo das sessões? - Considera adequada a distribuição dos conteúdos nas diferentes sessões? - Considera que devem ser incluídos outros conteúdos ao programa?
Conhecer as perceções dos participantes relativamente à adequação das estratégias a utilizar nas sessões e os conteúdos abordados	Quais os conteúdos que devem ser abordados de acordo com a metodologia proposta?	- Considera adequados os conteúdos abordados nas sessões em grupo presenciais? - Considera adequado os conteúdos das sessões via zoom? - Considera adequados os conteúdos a abordar nos grupos de Facebook? - Considera adequados os conteúdos a abordar nos grupos de WhatsApp? - Considera adequado a existência de dois grupos distintos de WhatsApp, sendo que um se destina às pessoas diagnosticadas e o outro para os familiares? - Considera adequado a existência de dois grupos distintos de Facebook, sendo que um se destina às pessoas diagnosticadas e o outro para os familiares? - Considera adequado que os participantes possam partilhar com os pares e os profissionais as suas dúvidas e conquistas através do WhatsApp em grupos distintos (um para as pessoas diagnosticadas e outro para os familiares)?

Objetivo 3: Conhecer quais são as caraterísticas definidoras de um programa de intervenção psicoeducativa de Enfermagem com as pessoas com Diabetes tipo 2 e família relativamente à sua metodologia

Objetivos específicos	Questões – Chave	Tópicos de questões a explorar no debate
Conhecer as perceções dos participantes relativamente às estratégias a utilizar na implementação do programa de intervenção	Quais as estratégias mais adequadas a utilizar na implementação do programa desenvolvido com as pessoas com Diabetes tipo 2 e família?	- Considera adequadas as estratégias descritas nas sessões em grupo via zoom? - Considera adequadas as estratégias descritas para nas sessões presenciais? - Considera adequado o uso de jogos interativos nas sessões em grupo? - Considera que o recurso a novas tecnologias (grupos de WhatsApp e Facebook) adequado? - Considera que o recurso a novas tecnologias (grupos de WhatsApp e Facebook) pode potenciar os ganhos em saúde dos participantes? - Considera adequado manter os grupos de WhatsApp e Facebook ativos até ao final do *follow-up*?
	Quais as metodologias mais conducentes a uma ma participação das pessoas com DM e família?	- Quais considera serem as estratégias que promovem uma maior participação das pessoas diagnosticadas ao programa? - Quais considera serem as estratégias que promovem uma maior participação da família no programa? - Considera que o recurso a novas tecnologias (sessões via Zoom) pode aumenta é uma mais valia na implementação do programa?
	Considera importante as estratégias de *follow-up?*	- Quais considera serem as melhores estratégias para a realização de *follow-up*? - Considera adequado a realização de telefonemas como estratégia de *follow-up*? - Considera adequado o período definido de 6 meses de *follow-up*, após o término do programa?