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Family Involvement and Diabetes Distress across Dyads for Adults with Type 2 Diabetes

McKenzie K. Roddy, PhD^{1,2,3}, Lyndsay A. Nelson, PhD^{2,3}, Andrew J. Spieker, PhD⁴, Robert A. Greevy Jr., PhD⁴, Lindsay S. Mayberry, PhD, MS^{2,3}

¹Quality Scholars Program, VA Tennessee Valley Healthcare System, Nashville, TN, USA

²Center for Health Behavior and Health Education, Vanderbilt University Medical Center, Nashville, TN, USA

³Department of Medicine, Vanderbilt University Medical Center, Nashville, TN, USA

⁴Department of Biostatistics, Vanderbilt University Medical Center, Nashville, TN, USA

Abstract

Objective: Family/friend involvement and diabetes distress are associated with outcomes for persons with type 2 diabetes (PWDs), but little is known about how they relate to each other. We aim to (1) describe associations between PWD and support person (SP) distress; (2) describe associations between involvement and diabetes distress for PWDs, for SPs, and across the dyad; and (3) explore whether associations differ by PWD-SP cohabitation.

Methods: PWDs and SPs co-enrolled in a study evaluating the effects of a self-care support intervention and completed self-report measures at baseline.

Results: PWDs and SPs (N=297 dyads) were, on average, in their mid-50s and around onethird identified as a racial or ethnic minorities. The association between PWD and SP diabetes distress was small (Spearman's ρ =0.25, p<0.01). For PWDs, experienced harmful involvement from family/friends was associated with more diabetes distress (standardized β =0.23, p<0.001) independent of helpful involvement in adjusted models. Separately, SPs' self-reported harmful involvement was associated with their own diabetes distress (standardized β =0.35, p<0.001) and with PWDs' diabetes distress (standardized β =0.25, p=0.002), independent of SPs' self-reported helpful involvement.

Corresponding Author: Lindsay S. Mayberry, MS, PhD, 2525 West End Ave. Suite 450, Nashville, TN 37203, Phone: (615) 875-5821, Fax: (615) 875-2201, lindsay.mayberry@vumc.org.

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Conclusion & Practice Implications: Findings suggest dyadic interventions may need to address both SP harmful involvement and SP diabetes distress, in addition to PWD distress.

Keywords

type 2 diabetes; family involvement; diabetes distress; social support; dyad

1. Introduction

Around 10% of the global population is expected to have diabetes by 2040 [1, 2], with type 2 diabetes accounting for 87% to 91% of cases globally [3]. In the United States, the estimated prevalence of type 2 diabetes was 9.3% in 2020[4] and is expected to increase [5]. One common complication of type 2 diabetes is experiencing emotional distress related to diabetes. Around 36% of persons with type 2 diabetes (PWDs) report clinically significant diabetes distress [6], or levels of distress above a validated cutoff associated with reduced self-care and poor adherence. Diabetes distress explains variance in glycemic management over and above age, diabetes distress are associated with worse glycemic management [8, 9].

Management of type 2 diabetes requires self-care which largely occurs within social contexts of individuals [10–12]; therefore, social contexts impact diabetes distress. For this reason, assessments of diabetes distress explicitly contain social components. For example, the Diabetes Distress Scale [13] queries if family/friends appreciate the difficulty of living with diabetes and the Problem Areas in Diabetes [14] assesses uncomfortable interactions around diabetes with family/friends.

Family/friend involvement in diabetes management can impact outcomes and the experience of distress. Harmful involvement, including arguing and presenting barriers to self-care is cross-sectionally associated with worse self-care [15, 16] and longitudinally associated with worse glycemic management [17]. In contrast, helpful involvement, including problem solving and facilitating self-care, is associated with better diabetes self-care and glycemic management cross-sectionally [18–21] and longitudinally [12, 22]. More frequent involvement with medically-focused activities (e.g., taking medications and self glucose testing) is associated with higher diabetes distress for PWD, but more frequent involvement with diet or physical activity is not [23]. Greater harmful involvement and higher diabetes distress are associated, above and beyond the effects of general life stress [24]. Finally, greater helpful involvement is associated with lower diabetes distress only among PWD who infrequently use social interactions to modulate emotional experiences [24].

In addition to adults with type 2 diabetes, close family/friends also experience distress related to their loved ones' diabetes [25]. Global estimates from the second Diabetes Attitudes, Wishes, and Needs (DAWN2) study suggest 40% of cohabitating family of PWD experience clinically significant diabetes distress [26]. Moreover, 35% of family reported a notable burden of diabetes on the family and 37% reported frustration they did not know how to best support the PWD [26]. Associations between PWD distress and support person

There may be associations between SP involvement and SP distress, which would have important implications for understanding social contexts where PWDs are managing their health and inform intervention development. Additional analyses from the DAWN2 study found higher family member diabetes distress is associated with greater perceived diabetes severity, higher worry about hypoglycemia, and more arguments and frustration about diabetes and helping PWDs [27]. These findings suggest experiencing distress related to loved ones' diabetes may be associated with how family members communicate about diabetes and self-care for cohabitating dyads. More work is needed to understand associations between diabetes-focused involvement and distress for SPs, cohabitating or not. Additionally, it is unclear whether associations between family involvement and distress are modified by social context – specifically if cohabitating dyads have different intensities or directions of these associations than non-cohabitating dyads. Such differences, if identified, would have implications for who to include in dyadic interventions. Finally, there is limited research on cross-dyad associations between SPs and PWDs. Existing evidence points to possible pathways across dyads: higher diabetes distress for friends/family is associated with worse glycemic management and increased cardiac risk for PWDs [23]. However, PWD-reported frequency of SP involvement was not associated with SP diabetes distress [23]. We sought to replicate some of these findings and extend this line of research to address these gaps.

1.1 Aims

In Aim 1, we aim to describe associations between PWDs' and SPs' diabetes distress. In Aim 2, we aim to describe associations between (a) PWDs' experience of family/friend involvement and PWDs' diabetes distress, (b) SPs' self-reported involvement and SPs' diabetes distress, and (c) SPs' self-reported involvement and PWDs' diabetes distress. In Aim 3, we aim to explore if the magnitude of associations in aim 2 are different for cohabitating and non-cohabitating dyads.

2. Methods

Participants were recruited for a randomized control trial (RCT) testing the efficacy of a family-focused self-care support intervention for adults with type 2 diabetes (ClinicalTrials.gov NCT04347291). The current study is a secondary analysis of baseline data [28].

1.2 Participants

To be eligible, PWDs needed to be 18–75 years old, diagnosed with type 2 diabetes, community dwelling, prescribed daily diabetes medication, and to speak and read English and own a mobile phone. PWDs were excluded if they were currently using hospice or dialysis services, undergoing treatment for cancer, pregnant, had congestive heart failure, dementia, or schizophrenia, or if they disclosed recent abuse during a brief screener. Of 335 participants who were randomized in the larger RCT, 297 co-enrolled SPs, defined

as someone with whom PWDs felt comfortable discussing diabetes and health goals. SPs needed to be 18 years old, speak and read in English, and own a mobile phone (different from the PWD participant's phone) and were excluded if they were unable to receive and respond to texts after training by research assistants. There were no other exclusion criteria for SPs.

Because we were interested in associations across dyads, these analyses exclude PWD who participated in the trial without SPs (n=38). We therefore analyzed 297 PWD/SP dyads.

2.2 Procedures

Potentially eligible PWDs receiving primary care from a large academic medical center in the Southeast were identified using data derived from the electronic medical record (EMR). We identified PWDs having a most recent hemoglobin A1c (HbA1c) value 7.5% and then prioritized recruitment of PWDs with HbA1c 8.5%, from a minoritized racial or ethnic group, and/or having no insurance or public insurance only to ensure representation of individuals who met any or multiple of these criteria in the study sample. Potentially eligible PWDs were sent an opt-out letter about the study and contacted by phone by research assistants to assess interest, confirm eligibility, and complete verbal informed consent for the RCT. PWDs were asked to identify a SP to co-enroll in the study who was then contacted by research assistants to assess eligibility and enroll. Consenting PWDs and SPs were sent a survey via REDCap link via email or paper by mail, per participant preference. Additionally, PWDs completed a mailed HbA1c kit at enrollment. All procedures were approved by the Vanderbilt University Institutional Review Board.

2.3 Measures

PWDs and SPs self-reported demographic characteristics including age, years of education, gender, race, ethnicity, and income. Additionally, PWDs reported insurance status, diabetes duration, and insulin use. Finally, SPs reported their relationship type with the PWD (e.g., spouse, friend) and if they were cohabiting with the PWD at the time of enrollment.

2.3.1 Glycemic management.—HbA1c kits analyzed by CoreMedica Laboratories (Lee's Summit, MO), which have been validated against venipuncture [29], were used to collect HbA1c. When kit results were not returned, recent HbA1c were extracted from the EMR. Higher HbA1c indicates worse glycemic management.

2.3.2 Family/Friend Involvement in Adult Diabetes.—PWDs completed the 9-item helpful and 7-item harmful scales of the Family/Friend Involvement in Adults' Diabetes (FIAD) reporting on received involvement from their family/friends [17]. PWDs reported on involvement received or experienced from multiple sources – not exclusively that received from their SP. All items follow the stem "How often do your friends or family members...;" an example item from the helpful subscale is "ask how they can help you with your diabetes," and an example item from the harmful subscale is "argue with you about your food choices or your health." PWDs reported on a 5-point scale from 1="never in the past month" to 5="twice or more each week." Items are averaged within each subscale. Good internal consistency reliability and high test-retest reliability of the

FIAD has been established in prior samples [17, 24]. In the current sample of PWDs, internal consistency reliability was good for helpful involvement (α =0.88) and acceptable for harmful involvement (α =0.60) [30].

SPs completed the 9-item helpful and 7-item harmful scales of the FIAD family/friend version (herein FIAD-SP). Validation [30] of the FIAD measure among PWDs did not include examination of the psychometric properties of the FIAD-SP, therefore we conducted an exploratory factor analysis with a varimax rotation with Kaiser normalization, consistent with the PWD FIAD validation. The FIAD-SP had a two-factor solution; Eigenvalues 3.9 and 1.7, explaining cumulative 94% variance. All helpful items loaded onto the first factor with loadings >.4; four of the seven harmful items loaded onto the second factor with loadings >.4 but three (item #5, 6, and 15) had lower loadings. We examined item frequencies and construct validity with and without these items and determined they should be retained because (a) the harmful scale is a composite of numerous behaviors (undermining, criticism, arguing, miscarried help) and these items assess undermining whereas the other items assess criticism, arguing and miscarried help, (b) low factor loadings were likely a function of items #6 and 15 being rarely endorsed, and (c) the correlations between measures designed to assess helpful/supportive involvement (FIAD-SP helpful and the DAWN Family Support Scale-Family Member version [31]) were lower with the full 7-item version than with the reduced 4-item version, suggesting removal of these items negatively impacted construct (divergent) validity of the FIAD-SP harmful scale. Thus, we examined the 7-item harmful scale (a=0.52) of the FIAD-SP alongside the 9-item helpful scale (α =0.87), consistent with the PWD version of the FIAD.

2.3.3 Diabetes distress.—PWDs completed the 5-item Problem Areas in Diabetes (PAID) reporting on distress specific to diabetes [14]. SPs completed the 5-item PAID-DAWN2 Family Member (PAID-DFM [26]) reporting on their own distress specific to the PWD's diabetes. Items were scored on a 5-point scale from 0="not a problem" to 4="serious problem." An example item is "feeling scared when you think about [the fact that PWD is] living with diabetes." Summed scores were multiplied by 5 to create a 100-point total scale. Scores 40 indicate clinically meaningful diabetes distress. Both versions of the PAID had good reliability in the current sample (α_{PAID} =0.91, α_{PAID} -DFM=0.81).

2.4 Analysis Plan

We used non-parametric tests of association (Spearman's ρ) and linear regression with robust standard errors (HC3) to test for associations. In adjusted models, a priori covariates include age, gender, and race/ethnicity of outcome reporters. Adjusted models predicting PWD distress also included a priori covariates PWD income, years of education, diabetes duration, and insulin use. Finally, we conducted an adjusted subgroup analyses for cohabitating and non-cohabitation dyads examining betas rather than relying on statistical significance due to the smaller sample of non-cohabitating dyads.

Variables of interest were missing <5% and were not imputed. Covariates were missing for individual variables between 0.0% and 5.1%; however, 5.7% of PWDs and 10.1% of SPs would be dropped from adjusted models due to missing covariates. Therefore, we mean

imputed missing continuous covariates and conservatively classified missing categorical covariates. We ran models once using casewise deletion and once with mean imputations and results were consistent; therefore, we report results using mean imputation. Full results are available from the authors.

3. Results

3.1 Sample Description

Among the 297 PWDs who enrolled SPs, 51.5% were male and the average age was 56.8 years (SD=11.1); 36.7% reported a minoritized racial or ethnic background, 33.8% reported an annual household income <\$50,000, and 19.9% had public insurance only or were uninsured. With regards to diabetes characteristics, PWDs reported an average diabetes duration of 11.5 (SD=8.1) years, 37.0% used insulin, and average baseline HbA1c was 8.7% (SD=1.7%). Among the 297 SPs, 27.9% were male and the average age was 52.0 years (SD=14.4); 31.6% reported a minoritized racial or ethnic background and 27.3% reported an annual household income <\$50,000 (see Table 1). Most SPs reported the PWD was their spouse or partner (58.6%), followed by 31.0% other family members and 8.1% friends; 71.4% reported living with the PWD. Almost all spouse/partner dyads were also cohabitating (97.7%).

PWDs' report of experienced involvement from multiple sources and SPs' self-report of their involvement were largely consistent. According to PWDs and SPs, the most frequently endorsed helpful behaviors were gently talking about taking care of their diabetes, praise for eating healthy foods or following exercise routine, and asking to help with diabetes. Helpful behaviors were endorsed more frequently than harmful behaviors. The most frequently endorse harmful behaviors for PWDs and SPs were bringing foods around they shouldn't be eating and arguing about food choices or health. See Table 2 for full results.

3.2 Associations between PWD and SP Diabetes Distress

Nearly half of PWDs (48.8%) and 38.4% of SPs reported clinically significant diabetes distress with 59.3% concordance among dyads. The correlation between PWD and SP diabetes distress was significant, though modest (ρ =0.25, p<0.01). Correlations between PWD and SP diabetes distress were not statistically different between cohabitating and non-cohabitating dyads (ρ =0.28 [95%CI: 0.14, 0.40] vs. ρ =0.21 [95%CI: -0.02, 0.41]; p=0.57) nor for partnered and unpartnered dyads (ρ =0.29 [95%CI: 0.14, 0.42] vs. ρ =0.21 [95%CI: 0.20, 0.38]; p=0.51).

3.3 Associations Between Family/Friend Involvement and Diabetes Distress

Results for cross-sectional associations between involvement and diabetes distress are displayed in Table 3. Lower diabetes distress for PWDs was associated with being younger and male in Aims 2a and 2c. We did not detect any significant relationships between tested covariates and SP diabetes distress in Aim 2b. PWDs' experience of more harmful involvement from multiple family/friends was associated with higher diabetes distress ($\beta_{adjusted}$ =0.23, 95% CI: 0.10, 0.35). Similarly, SPs' self-reporting more of their own harmful involvement in the PWDs' diabetes had higher distress about the PWDs' diabetes

 $(\beta_{adjusted}=0.35, 95\%$ CI: 0.22, 0.47). Finally, SPs self-reporting more harmful involvement had a linked PWD reporting higher diabetes distress ($\beta_{adjusted}=0.25, 95\%$ CI: 0.10, 0.40).

3.4 Associations by Cohabitation

We examined the associations between involvement and diabetes distress separately for cohabitating and non-cohabitating dyads (because nearly all partnered dyads were cohabitating, we did not separately examine partnered vs. non-partnered dyads). The association between PWDs' experience of harmful involvement from multiple family/friends and diabetes distress was stronger among PWD who did not cohabitate with their enrolled SP (cohabiting $\beta_{adjusted}$ =0.56, 95%CI: 0.30, 0.82 vs. non-cohabitating $\beta_{adjusted}$ =0.11, 95%CI: -0.03, 0.24). The association between SPs' self-report of their own harmful involvement and their own distress about the PWDs' diabetes was consistent across cohabitating and non-cohabitating dyads (cohabiting $\beta_{adjusted}$ =0.36 95%CI: 0.23, 0.49; non-cohabiting $\beta_{adjusted}$ =0.37 95%CI: -0.06, 0.79). Finally, the across-dyad association between self-reported harmful involvement by the SP and PWD distress was stronger among cohabiting dyads (cohabitating $\beta_{adjusted}$ =0.27, 95%CI: 0.09, 0.45 vs. non-cohabitating $\beta_{adjusted}$ =0.19, 95%CI: -0.15, 0.52).

4. Discussion and Conclusion

4.1 Discussion

Harmful involvement of family/friends in PWDs' management of type 2 diabetes matters for distress in multiple ways. First, for PWDs, the aggregate received harmful involvement from multiple family/friends was associated with higher distress, replicating prior findings that harmful involvement and diabetes distress are associated [24] with a different measure of diabetes distress. This may be especially true for PWDs whose SP does not cohabitate. Given that higher levels of diabetes distress are associated with worse self-care and glycemic management [8, 9, 23], harmful family/friend involvement is likely a modifiable factor that could help to improve glycemic management as well as diabetes distress.

Second, self-reported harmful involvement performed by SPs was associated with their own distress about the PWDs' diabetes, regardless of cohabitation. It could be that distressed SPs engage in more nagging and arguing because diabetes distress could inspire harmful involvement in those without training in how to be helpful or use autonomy supportive communication. Alternately, harmful involvement may lead to diabetes distress for SPs because their attempts to be involved are poorly received or ineffective. For example, the DAWN2 study found more arguments about helping the PWD were associated with greater family member diabetes distress [27]. Finally, the association may be spurious: in reaction to PWDs who are perceived as avoiding their diabetes self-management, SPs could experience both distress and engage harmfully.

Third, across the dyad, self-reported harmful involvement performed by SPs was also associated with higher diabetes distress for PWDs. These associations may be stronger for cohabitating than non-cohabitating dyads. Dyadic interventions may need to target social contexts in addition to PWDs: SP involvement and SP distress in addition to PWD distress.

Furthermore, associations between harmful involvement and diabetes distress may be different depending on cohabitation, which has implications for who are considered for family interventions for adults with chronic conditions. SP self-report of their own harmful involvement appears to have a stronger relationship with PWD distress when the dyad is cohabitating. In contrast, PWDs' report of received or experience harmful involvement from all family/friends may have a stronger relationship with their own distress when the PWD selected a non-cohabitating SP. Of note, we are not able to differentiate harmful involvement from the designated SP versus family in general in PWDs' reports. Therefore, PWDs with a non-cohabitating SP may live with family/friends who are harmfully involved and chosen someone outside the home to participate in the study, reflecting a decision to forgo proximity for someone they perceived as more supportive, or if they live alone, the harmful involvement could come from external sources. More work is needed to understand how these associations differ in varying social situations. In the United States, up to 7 million American report receiving care from someone outside the home [32], and most older adults (78%) have weekly contact with adult children living outside their home [32]. Given the prevalence of out-of-home support, findings here are timely to support an inclusive conceptualization of family when designing interventions to support PWD. Finally, these findings highlight the impacts of diabetes distress on social systems.

4.1.1 Limitations.—We were unable to draw conclusions about causality due to the cross-sectional nature of this work; however, there are likely reciprocal relationships between family/friend involvement and distress. Second, SPs may be unaware of their own harmful behaviors or struggle to endorse certain items due to social desirability bias. Finally, because PWDs reported on involvement received from multiple sources of friends and family, versus only their identified SP, we were unable to assess associations between involvement for PWDs and SP diabetes distress. Prior work did not find associations between PWD-reported frequency of involvement and SP diabetes distress [23]; therefore, future work could conduct a full actor-partner interdependence model to investigate the relationships.

4.2 Conclusions

This work adds to the body of research understanding how the social context in which PWDs are managing diabetes is associated with their psychological well-being. Modest but significant associations between PWD and SP diabetes distress suggest there may be highly distressed dyads in particular need of intervention. Additionally, understanding how the involvement and distress of close friends and family members is associated with PWDs' experiences is key for future dyadic intervention development.

4.3 Practice Implications

Enquiring about the received support and social context in which PWDs are performing daily self-care behaviors could uncover important considerations for diabetes management. First, as a field, we should adopt an inclusive definition of social support to include family and friends, locally and long distance, with whom PWDs discuss their diabetes and health goals. Second, providers should explicitly inquire about helpful and harmful behaviors that are occurring – or the absence of desired helpful behaviors. By understanding the full

picture of self-management support, we can better help PWDs problem solve and offer more personalized resources.

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I confirm all patient/personal identifiers have been removed or disguised so the patient/person(s) described are not identifiable and cannot be identified through the details of the story.

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References

- 1. Federation ID. Idf diabetes atlas. 2013. Brussels, Belgium: International Diabetes Federation, 6th edn. 2015.
- Holman N, Forouhi N, Goyder E, Wild S. The Association of Public Health Observatories (APHO) diabetes prevalence model: estimates of total diabetes prevalence for England, 2010–2030. Diabetic Medicine. 2011;28:575–82. [PubMed: 21480968]
- 3. Shaw JE, Sicree RA, Zimmet PZ. Global estimates of the prevalence of diabetes for 2010 and 2030. Diabetes research and clinical practice. 2010;87:4–14. [PubMed: 19896746]
- 4. Statistics NCfH. Interactive Summary Health Statistics for Adults-2019. 2021.
- 5. Kaiser AB, Zhang N, Der Pluijm WV. Global Prevalence of Type 2 Diabetes over the Next Ten Years (2018–2028). Diabetes. 2018;67:202–LB.
- Perrin NE, Davies MJ, Robertson N, Snoek FJ, Khunti K. The prevalence of diabetes-specific emotional distress in people with Type 2 diabetes: a systematic review and meta-analysis. Diabet Med. 2017;34:1508–20. [PubMed: 28799294]
- Polonsky WH, Anderson BJ, Lohrer PA, Welch G, Jacobson AM, Aponte JE, et al. Assessment of diabetes-related distress. Diabetes care. 1995;18:754–60. [PubMed: 7555499]
- Indelicato L, Dauriz M, Santi L, Bonora F, Negri C, Cacciatori V, et al. Psychological distress, self-efficacy and glycemic control in type 2 diabetes. Nutr Metab Cardiovasc Dis. 2017;27:300–6. [PubMed: 28274728]
- Asuzu CC, Walker RJ, Williams JS, Egede LE. Pathways for the relationship between diabetes distress, depression, fatalism and glycemic control in adults with type 2 diabetes. J Diabetes Complications. 2017;31:169–74. [PubMed: 27746088]
- Bennich BB, Røder ME, Overgaard D, Egerod I, Munch L, Knop FK, et al. Supportive and non-supportive interactions in families with a type 2 diabetes patient: an integrative review. Diabetology & Metabolic Syndrome. 2017;9:1–9. [PubMed: 28053672]
- 11. Glasgow RE, Toobert DJ. Social environment and regimen adherence among type II diabetic patients. Diabetes care. 1988;11:377–86. [PubMed: 3391088]
- Nicklett EJ, Heisler MEM, Spencer MS, Rosland A-M. Direct social support and long-term health among middle-aged and older adults with type 2 diabetes mellitus. Journals of Gerontology Series B: Psychological Sciences and Social Sciences. 2013;68:933–43. [PubMed: 24150176]
- Polonsky WH, Fisher L, Earles J, Dudl RJ, Lees J, Mullan J, et al. Assessing psychosocial distress in diabetes: development of the diabetes distress scale. Diabetes care. 2005;28:626–31. [PubMed: 15735199]
- McGuire B, Morrison T, Hermanns N, Skovlund S, Eldrup E, Gagliardino J, et al. Short-form measures of diabetes-related emotional distress: the Problem Areas in Diabetes Scale (PAID)-5 and PAID-1. Diabetologia. 2010;53:66–9. [PubMed: 19841892]

- Henry SL, Rook KS, Stephens MA, Franks MM. Spousal undermining of older diabetic patients' disease management. Journal of Health Psychology. 2013;18:1550–61. [PubMed: 23325381]
- Stephens MAP, Franks MM, Rook KS, Iida M, Hemphill RC, Salem JK. Spouses' attempts to regulate day-to-day dietary adherence among patients with type 2 diabetes. Health Psychology. 2013;32:1029. [PubMed: 23025302]
- Mayberry LS, Berg CA, Greevy RA Jr., Wallston KA. Assessing helpful and harmful family and friend involvement in adults' type 2 diabetes self-management. Patient Educ Couns. 2019;102:1380–8. [PubMed: 30922622]
- Mayberry LS, Osborn CY. Family involvement is helpful and harmful to patients' self-care and glycemic control. Patient education and counseling. 2014;97:418–25. [PubMed: 25282327]
- Rosland A-M, Kieffer E, Israel B, Cofield M, Palmisano G, Sinco B, et al. When is social support important? The association of family support and professional support with specific diabetes self-management behaviors. Journal of general internal medicine. 2008;23:1992–9. [PubMed: 18855075]
- Wen LK, Shepherd MD, Parchman ML. Family support, diet, and exercise among older Mexican Americans with type 2 diabetes. The Diabetes Educator. 2004;30:980–93. [PubMed: 15641619]
- Walker RJ, Smalls BL, Egede LE. Social determinants of health in adults with type 2 diabetes —Contribution of mutable and immutable factors. Diabetes research and clinical practice. 2015;110:193–201. [PubMed: 26411692]
- Nicklett EJ, Liang J. Diabetes-related support, regimen adherence, and health decline among older adults. Journals of Gerontology Series B: Psychological Sciences and Social Sciences. 2010;65:390–9.
- 23. Lee AA, Heisler M, Trivedi R, Obrosky DS, Mor MK, Piette JD, et al. Diabetes distress among dyads of patients and their health supporters: links with functional support, metabolic outcomes, and cardiac risk. Annals of Behavioral Medicine. 2021;55:949–55. [PubMed: 33044495]
- 24. Leukel PJ, Kollin SR, Lewis BR, Lee AA. The influence of emotion regulation and family involvement on diabetes distress among adults with type 2 diabetes. Journal of Behavioral Medicine. 2022:1–10.
- 25. Stödberg R, Sunvisson H, Ahlström G. Lived experience of significant others of persons with diabetes. Journal of clinical nursing. 2007;16:215–22.
- 26. Kovacs Burns K, Nicolucci A, Holt RI, Willaing I, Hermanns N, Kalra S, et al. Diabetes Attitudes, Wishes and Needs second study (DAWN2TM): Cross-national benchmarking indicators for family members living with people with diabetes. Diabetic Medicine. 2013;30:778–88. [PubMed: 23701236]
- 27. Kovacs Burns K, Holt RI, Nicolucci A, Lucisano G, Skovlund SE, Comaschi M, et al. Correlates of psychological outcomes among family members of people with diabetes in the second Diabetes Attitudes, Wishes and Needs (DAWN2TM) study. Diabet Med. 2016;33:1184–93. [PubMed: 27086909]
- Mayberry LS, El-Rifai M, Nelson LA, Parks M, Greevy RA Jr, LeStourgeon L, et al. Rationale, design, and recruitment outcomes for the family/friend activation to motivate self-care (FAMS) 2.0 randomized controlled trial among adults with type 2 diabetes and their support persons. Contemporary Clinical Trials. 2022:106956. [PubMed: 36208719]
- Fokkema MR, Bakker AJ, de Boer F, Kooistra J, de Vries S, Wolthuis A. HbA1c measurements from dried blood spots: validation and patient satisfaction. Clinical Chemistry and Laboratory Medicine (CCLM). 2009;47:1259–64. [PubMed: 19751141]
- 30. George D, Mallery P. IBM SPSS statistics 26 step by step: A simple guide and reference: Routledge; 2019.
- 31. Burns KK, Nicolucci A, Holt R, Willaing I, Hermanns N, Kalra S, et al. Educational and Psychological Issues Diabetes Attitudes, Wishes and Needs Second Study (DAWN2TM): crossnational benchmarking indicators for family members living with people with diabetes. Diabetic Medicine. 2013;30:778–88. [PubMed: 23701236]
- Piette JD, Rosland AM, Silveira M, Kabeto M, Langa KM. The case for involving adult children outside of the household in the self-management support of older adults with chronic illnesses. Chronic illness. 2010;6:34–45. [PubMed: 20308349]

Highlights

- For people with diabetes, harmful involvement was associated with higher distress
- Family may engage harmfully when they are distressed about the patients' diabetes
- Family engaging harmfully may lead to their own distress
- This is the first study, known to us, to demonstrate associations across the dyad
- Harmful has greater impact than lack of helpful involvement for diabetes distress

Table 1:

Sample Characteristics

	PWDs (N=297)			SPs =297)	
	M/N	SD/%	M/N	SD/%	
Demograph	hic Char	acteristics	,		
Age (years)	56.8	11.1	52.0	14.4	
Education (years)	15.3	2.9	14.9	2.5	
Male	153	51.5%	83	27.9%	
Race/Ethnicity					
Non-Hispanic white	185	62.3%	183	61.6%	
Non-Hispanic black	68	22.9%	64	21.5%	
Hispanic	22	7.4%	14	4.7%	
NH-Other	19	6.4%	16	5.4%	
Missing	3	1.0%	20	6.7%	
Annual household income ((USD)				
<\$10K	5	1.7%	7	2.4%	
\$10-24.9K	29	9.8%	13	4.4%	
\$25-34.9K	18	6.1%	24	8.1%	
\$35–49.9K	48	16.2%	37	12.5%	
\$50–74.9K	55	18.5%	52	17.5%	
\$75–99.9K	34	11.4%	45	15.2%	
>\$100K	97	32.7%	92	31.0%	
Missing/unknown	11	3.7%	27	9.1%	
Insurance					
Uninsured	4	1.4%			
Private	229	77.1%			
Public only	55	18.5%			
Missing	8	2.7%			
Diabetes Duration (years)	11.5	8.1			
Insulin	110	37.0%			
HbA1c (%)	8.7	1.7			
Relationship Character	istics, Pi	redictors, a	& Outco	omes	
Relationship Type					
Spouse/Partner			174	58.6%	
Other Family			92	31.0%	
Friend			24	8.1%	
Missing			7	2.4%	
Cohabitation			212	71.4%	
Helpful Involvement	2.3	1.0	2.6	0.9	
Harmful Involvement	1.7	0.6	1.5	0.5	
Diabetes Distress	38.9	25.7	32.7	21.8	

Note: PWDs = persons with diabetes; SPs = support persons; HbA1c = hemoglobin A1c.

Table 2:

Endorsement of FIAD items for PWDs and SPs

		Persons with Diabetes				Support Persons			
Item Text (written for PWD)	N	Mean	SD	%	N	Mean	SD	%	
Helpful Subscale									
Exercise with you or ask you to exercise with them?	294	2.04	1.5	41%	286	2.1	1.4	46%	
Gently talk with you about taking care of your diabetes?	294	2.6	1.3	72%	283	3.0	1.3	82%	
Help you decide if changes should be made based on your blood sugar testing results?	291	2.2	1.4	51%	285	2.6	1.4	67%	
Ask how they can help you with your diabetes?	294	2.5	1.4	64%	285	2.7	1.4	71%	
Suggest things that might help you take your diabetes medicine when you are supposed to?	294	2.2	1.5	46%	282	2.5	1.5	58%	
Praise you for eating healthy foods or following your exercise routine?	294	2.6	1.4	68%	286	3.0	1.4	79%	
Help you choose healthy foods, for example by reading food labels or helping you choose from a menu?	293	2.5	1.5	59%	285	2.7	1.5	66%	
Prepare or plan healthy foods to help with your recommended diet?	294	2.7	1.6	64%	285	3.0	1.6	69%	
Take on one of your responsibilities, so you can have time to exercise?	293	1.6	1.2	26%	284	1.9	1.4	33%	
Harmful Subscale									
Point out in front of others when you are eating unhealthy foods, like at a party or get-together?	294	1.8	1.2	37%	285	1.3	0.8	19%	
Bring foods around that you shouldn be eating?	293	2.7	1.5	70%	286	2.4	1.3	61%	
Tell you diabetes is your problem to deal with on your own?	293	1.1	0.4	4%	285	1.1	0.4	3%	
Argue with you about your food choices or your health?	293	1.8	1.2	41%	282	1.8	1.3	1.3 36%	
Criticize you for not testing your blood sugar?	293	1.6	1.1	28%	286	1.5	0.9	0.9 24%	
Criticize you for not exercising?	294	1.7	1.2	31%	286	1.4	0.8	21%	
Suggest you don need to take your diabetes medicine?	293	1.1	0.5	3%	284	1.0	0.2	0%	

Note: The percent represents the number who endorsed this item happening at least once in the last month out of the total sample (n=297).

Table 3:

Unadjusted and Adjusted Associations between Involvement and Diabetes Distress

	Unadjusted		Adjusted		Cohabitating - Adjusted		Non- Cohabitating - Adjusted	
	Beta	р	Beta	р	Beta	р	Beta	р
PWD Diabetes Distress								
Experienced Helpful Involvement by PWD	0.01	0.92	0.05	0.46	0.15	0.09	-0.18	0.16
Experienced Harmful Involvement by PWD	0.19	0.005	0.23	<.001	0.11	0.12	0.56	<.001
SP Diabetes Distress								
Self-reported Helpful Involvement of SP	0.03	0.57	0.03	0.64	0.06	0.38	0.02	0.85
Self-reported Harmful Involvement of SP	0.33	<0.001	0.35	<.001	0.36	<.001	0.37	0.09
PWD Diabetes Distress								
Self-reported Helpful Involvement of SP	0.04	0.48	0.04	0.43	0.11	0.09	-0.08	0.66
Self-reported Harmful Involvement of SP	0.20	0.008	0.25	0.002	0.27	0.003	0.19	0.27

Note: Adjusted models predicting PWD distress also include PWD education, diabetes duration, and insulin use (no insulin=0). Bolded terms indicate significant predictors. Cohabitating subgroup N = 212; non-cohabitating subgroup N = 78.