# The impact of type 2 diabetes diagnosis on married couples

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#### **Article points**

- 1. A diagnosis of type 2 diabetes impacts both the patient and his or her healthy partner, and can be a burden.
- Six themes were identified: tip of the iceberg; contradictory feelings; changes in daily living; amplifier of relational dynamics; the role of the healthy partner; and sharing is key.
- Mutual support within married couples reduces the burden of diabetes and improves outcomes; however, nurses should offer support to both patients and healthy partners to maximise positive outcomes.

#### Key words

- Diagnosis
- Couple
- Marriage - Support

See end of article

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Type 2 diabetes is a heavy burden for patients and their caregivers. Support provided by spouses has a positive influence on patient outcomes. This phenomenological descriptive study using semi-structured interviews explored the impact and meaning of diagnosis from the perspective of the patient and his/her spouse.

diagnosis of type 2 diabetes mellitus (T2DM) requires significant changes to lifestyle and the adoption of self-care (Bonds et al, 2004). It is often accompanied by life-long treatment regimens (Zhang et al, 2017). T2DM-related complications can lead to disability or even death (Iglay et al, 2016; Lallukka et al, 2016; Ha et al, 2017), and thus have a serious impact on quality of life for patients and their families (Lallukka et al, 2016; Caruso et al, 2018).

A growing body of literature has affirmed the positive influence caregivers have on patient health outcomes. Family and friends support and motivate T2DM patients to engage in glucose monitoring, healthier eating habits and physical activity (Oftedal et al, 2010; Caruso et al, 2015), improving clinical outcomes, the adoption of healthy lifestyles and emotional well-being (Strom and Egede, 2012). Notably, spousal support seems to have a stronger impact on treatment adherence than other relationships. Indeed, conjugal partners often face chronic illness together and are actively involved in its day-to-day management (Franks et al, 2010). Conjugal involvement is associated with positive patient outcomes (Franks et al, 2006) and emotional well-being (Coyne and Smith, 1991).

Despite the positive role of husbands and wives, a diagnosis of T2DM profoundly influences a couple's dynamics and inter-relationships (Martire et al, 2004). Current literature suggests that T2DM management is a source of marital stress (Berg and Upchurch, 2007), since the healthy partner is exposed to the same worries as the patient. Furthermore, the emotional costs of living with T2DM patients are significant (Wearden et al, 2000): spouses experience anxiety, feelings of isolation, guilt, frustration and anger towards the restrictions caused by T2DM (Morris et al, 2006). This study aimed to examine the impact and meaning of T2DM diagnosis on married couples.

#### **Methods**

COnsolidated The criteria for REporting Qualitative research (COREQ) Checklist was used to design this phenomenological descriptive research (Tong et al, 2007). Adults aged ≥18 years and married to a partner with a diagnosis of T2DM who was taking pharmacological (oral or insulin) therapy were eligible to participate. Selection was based on purposive sampling and the number of participants was guided by data saturation based on thematic analysis. Sampling continued until no further information would be gathered when a new couple was interviewed (Saunders et al, 2017).

Face-to-face semi-structured interviews were performed in Italian by an interviewer who had

received training in this technique. The couples were questioned (see Box 1) at home between May and July 2016. Each interview lasted between 30 and 45 minutes. The interviews were digitally recorded and then transcribed verbatim, ensuring confidentiality. Three independent researchers read the transcripts, in accordance with the Van Kaam method (Anderson and Eppard, 1998), to ensure the credibility, transferability and dependability of the data (Crowe et al, 2015). Quotations were translated from Italian into English following recommendations for achieving optimal representation of participants' experiences (van Nes et al, 2010). The research protocol was approved by the San Donato Hospital institutional board committee.

#### **Results**

Nine couples, aged between 30 and 67 years, participated in semi-structured interviews. Six husbands and three wives had a diagnosis of diabetes. The mean period of time since diagnosis was 7 years.

Six themes emerged through data analysis, each of which included sub-themes (see *Table 1*):

- Tip of the iceberg
- Contradictory feelings
- Changes in daily living
- An amplifier of relational dynamics
- The role of the healthy partner
- Sharing is key.

## Tip of the iceberg

A diagnosis of T2DM denotes the start of additional health problems for patients and as such it was defined by spouses as the "tip of the iceberg". T2DM frequently leads to complications and comorbidities, giving rise to disability, personal burden and social costs. For example, patients require frequent medical check-ups, such as blood and urine tests or cardiac and ophthalmologic monitoring. After T2DM diagnosis, patients often need drug therapy to achieve target blood glucose levels. Good adherence to drug therapy is essential, but it can cause the couple fatigue:

Interview 3: Husband : "I have to take 10–11 pills a day."

Wife: "I just wish he did not take all these medicines!"

#### Box 1. Questions asked during the semistructured interviews.

- Can you tell me how long ago you were diagnosed with type 2 diabetes [T2DM]?
- Can you tell me how you felt when you/your partner received a diagnosis of T2DM?
- How has the diagnosis changed your everyday life?
- What changes have you had to make since you/ your partner received his/her diagnosis?
- How do you manage T2DM as a couple?
- Is T2DM a source of disagreement or alliance?
- What are your expectations for the future, as a couple?
- Has a diagnosis of T2DM caused you to fear the future?

As often happens with a chronic disease that primarily affects middle-aged or older individuals, other medical conditions complicate the T2DM (Iglay et al, 2016). Comorbidities related to T2DM are associated with poor patient outcomes (Lin et al, 2015) and should be considered throughout patient management in order to optimise outcomes.

"Starting with this, more problems occurred – cholesterol, high blood pressure and so on. It was getting worse and worse. [I had] lots of problems not specifically linked to diabetes." (Interview 3)

T2DM patients have a greater chance of developing a variety of short- and long-term complications, especially as a result of poor blood glucose management (Iglay et al, 2016).

"He can't see because he had blood glucose values of 500 [27.8 mmol/L] for almost a year. He's got tough cataracts. He can't see at all." (Interview 5)

#### **Contradictory feelings**

It is normal for spouses to experience a range of contradictory feelings in the wake of T2DM. They can learn to manage these feelings and live a fulfilling life, however, through both functional and dysfunctional coping mechanisms (Nash, 2013). The feelings and reactions experienced immediately after diagnosis are unique and the coping mechanisms developed can define the T2DM management. Some develop functional coping mechanisms, accepting the problem and acting in a positive way:

#### Page points

- 1. Six themes emerged from thematic analysis of the semi-structured interviews.
- Partners identified diagnosis as the 'tip of the iceberg' as diabetes is progressive, requires changes in lifestyle and frequent medical checkups.
- 3. Patients and healthy partners have contradictory feelings when diabetes is diagnosed.

*"We, as a family, live with the difficult condition of the illness and find the positive meaning in this." (Interview 1)* 

Couples can live with feelings of anger, resignation and frustration caused by underestimation of the symptoms and impact of T2DM on their lives. When they fail to meet new and difficult situations, dysfunctional coping mechanisms can harden a couple's attitudes, leading to negative feelings:

"I was mad at him because I was telling him for a while to see a doctor and he didn't want to. I was mad at myself because I didn't recognise his symptoms which could be so obvious." (Interview 2)

Living with T2DM can lead to fear of the future, due to the high risk of acquiring complications:

"You can't heal the diabetes, and when I think that the situation can only get worse, I'm scared." (Interview 3)

The interviews demonstrated that over time spouses perceived T2DM management as a burden, leading to a negative impact on management and outcomes:

"Insulin irritates me; I don't want to do it anymore. It is a pain. To control it is hard — it is annoying." (Interview 4)

#### Changes in daily living

A T2DM diagnosis changes the couple's life. Daily living with T2DM is possible if the couple feels able to take responsibility for the disease through lifestyle modification for disease prevention and management. Spouses must know how to manage ailmentation, therapy and physical activity, as these will inevitably affect the couple's daily life. Furthermore, the changes in everyday life will follow the progression of the disease.

Many participants reported that one of the biggest difficulties was facing the symptoms:

"With diabetes you always feel tired, it is chronic tiredness. You are never in the mood for anything. I was doing only sofa—bed, bed—sofa. It was out of discussion to go out for walk." (Interview 3)

Mood swings are a frequent symptom that can be an obstacle in the couple's daily lives, especially for the healthy partner. Constant and faithful adherence to treatment is a priority that must be respected in any situation or condition. The healthy partner perceives this as "a therapy cage for the rest of their life": "You must inject the insulin, wherever you are, you have to do it. You have to carry it everywhere!" (Interview 7)

# The spouses agreed on the necessity of a healthy nutritious diet and adjusted their diet positively:

"What I eat, she also eats." (Interview 3)

"We've all changed our diet! Now, the new diet has become our lifestyle." (Interview 5)

#### An amplifier of relational dynamics

T2DM diagnosis heavily affects the balance of a relationship and is associated with changing aspects of the disease. The way couples deal with the impact of T2DM reflects their typical relational dynamics from before the diagnosis. In one interview, there was an obvious breakdown in the relationship ("I refuse to get her stuff ready, to make her food..." Interview 2). Another interviewee described how the diagnosis had led to increased quarrels and conflicts ("We first quarrelled, and now we argue!" Interview 4). T2DM diagnosis had, however, strengthened other relationships and led to a deeper union.

"We support each other. If it was not like this we wouldn't be together. We've had rough days. If we had not been united, our family would be disfigured." (Interview 3)

"We complete each other... Maybe [T2DM] united us." (Interview 5)

The healthy partner accommodates his or her lifestyle and habits to complement the patient's needs. For example, in interview 6 the patient said, "She too sacrifices and eats like me". T2DM management is based on solidarity.

#### The role of the healthy partner

The healthy partner becomes the patient's pillar of support, confiding in them and making suggestions:

"If sometimes I haven't followed a diet, it's because she told me: 'You can eat it a little bit, nothing happens'." (Interview 5)

# The healthy partner cares for and emotionally supports the patient, who relies entirely upon them:

"I'm lucky I have her: She is special because she comes with me everywhere. She doesn't scare me. She said: 'You can get well. You can control the disease'." (Interview 5) Some spouses describe how a symbiotic relationship emerges and results in positive outcomes including good management and lower disease burden:

"I stop the diet and he stops the diet! I gain weight and he gains weight!" (Interview 1)

## Diagnosis tends to change a couple's relationship. They often play different roles after T2DM onset.

"It was he who was cuddling me. He protected me! He got sick and everything collapsed! He was the column on which I was supported and it failed. It has been difficult." (Interview 5)

# Sharing is the key

The interviews illustrated the importance of sharing the difficulty, changes and management of T2DM. Sharing was a recurring theme, with participants saying "We've all changed our diet!" (Interview 5) and "We go to medical checkups together" (Interview 8). Sometimes the patient may require support if it is lacking:

"He doesn't do anything to help me! I do it alone if I need something. But is it not better if we do it together?" (Interview 4)

If trust in the healthy partner is very strong it enables good management of T2DM with positive outcomes. The patient tends to adhere to his/her therapeutic plan because he/she is motivated by the healthy partner in a strong relationship.

"She is my bible! I have extreme confidence in her!" (Interview 9)

# Discussion

T2DM management is key to optimising a patient's outcome and achievements. It includes adherence to pharmacological therapy, diet, lifestyle and physical activity (Van Puffelen et al, 2014) and thus has a high impact on a couple's daily life. The results of the interviews underline that both partners are completely involved in T2DM management. Sharing difficulties, changes and management is important when facing a diagnosis of T2DM (Anderson et al, 1990; Gibson et al, 2010).

The study highlighted that T2DM is a demanding disease, affecting couples' lives in many ways. Its management can be stressful, especially for the healthy partner (Lee et al, 2016). Couples defined T2DM as the "tip of the iceberg": the

# Table 1. The six themes and their sub-themes identified by thematic analysis.

Theme	Sub-themes
Tip of the iceberg	<ul> <li>Frequent medical check-ups</li> <li>Adherence with drug therapy</li> <li>Type 2 diabetes mellitus (T2DM) comorbidities</li> <li>T2DM complications</li> </ul>
Contradictory feelings	<ul> <li>Positive coping mechanisms</li> <li>Anger, resignation and frustration</li> <li>Fear for the future</li> <li>T2DM burden</li> </ul>
Changes in daily living	<ul> <li>Facing symptoms</li> <li>Mood swings</li> <li>Therapy cage</li> <li>Healthy nutrition</li> </ul>
An amplifier of relational dynamics	<ul> <li>Quarrels and conflicts</li> <li>Relationship break-up</li> <li>Deepening of the union</li> <li>Solidarity of the couple</li> </ul>
Role of the healthy partner	<ul> <li>Pillar of support</li> <li>Caring and emotional support</li> <li>Symbiotic relationship</li> <li>Reversal of roles</li> </ul>
Sharing is the key	<ul> <li>Sharing lifestyle and follow up</li> <li>Recognising the need for support</li> <li>Trust in the healthy partner</li> <li>Strong relationship</li> </ul>

beginning of additional health problems for the patient. Moreover, diagnosis arouses a range of contradictory feelings and emphasises the relational dynamics that characterised couples beforehand (Lister et al, 2016).

According to the literature (Franks et al, 2006; 2010) and the interviews we carried out, symbiotic relationships lead to positive T2DM outcomes as the patient's burden is decreased and the healthy partner is a pillar of support for the patient. At the same time, the healthy partner experiences stress related to his or her role change and the emotional costs associated with the burden of T2DM. The support process creates a balance in the T2DM couple's daily life based on sharing goals, achievements and failures.

It would be interesting to explore couples' quality of life before and after T2DM diagnosis. Assessing the self-efficacy and health determinants of couples (Caruso et al, 2017) may be useful in enhancing the confidence that they can achieve intended results. Self-efficacy strongly increases the person's ability to face challenges competently and influences the choices a person is most likely to make. Finally, assessing healthcare professionals' knowledge could allow specific training paths to be built to improve their professional competencies.

This study is the first to approach what T2DM diagnosis means for married couples. The literature is rich with studies of the consequences of T2DM on patients and their caregivers, but few authors have investigated the changes in marital relationship caused by T2DM. The results of this study have implications for nursing practice. Each member of the couple should be cared for. Nurses should consider couples as a single entity, investigating and recognising the needs of both husband and wife.

#### Limitations

The heterogeneity of participants' ages, time since T2DM diagnosis, rates of complications and selfcare behaviours are limitations of this study. The qualitative nature of the data mean that these results are not generalisable. The themes that emerged from couples' experiences are, however, potentially transferable to other, similar realities and could be the base on which further research into chronic illness can build. It was difficult to faithfully translate accounts from Italian into English, ensuring the nuances of meaning were retained. Following the recommendations made by van Nes et al (2012) for potentially reducing loss of meaning and enhancing the validity of cross-English qualitative research enabled us to optimise the representation of participants' experiences.

#### Conclusions

Living with T2DM can be challenging but couples should be able to lead a near-normal life. Couples try to create a new daily balance through sharing experiences and providing mutual support. These findings may have implications for nursing practice and research. It is important nurses be aware couples may be in crisis and need support or counselling to manage any unsupportive interactions.

- Anderson BJ et al (1990) Assessing family sharing of diabetes responsibilities. *J Pediatr Psychol* **15**: 477–92
- Anderson J, Eppard J (1998) Van Kaam's Method Revisited. *Qual Health Res* **8**: 399–403 Berg CA, Upchurch R (2007) A developmental-contextual model
- of couples coping with chronic illness across the adult life span. *Psychol Bull* **133**: 920–54
- Bonds DE et al (2004) The association of patient trust and self-care among patients with diabetes mellius. *BMC Fam Pract* **5**: 26
- Caruso R et al (2015) Physical activity, dietary habits and cognitive decline in over 65 years Italian outpatients with type 2 diabetes: a cross-sectional pilot study. *Int Diabetes Nurs* **12**: 69–73
- Caruso R et al (2017) Health determinants in Italian type 2 diabetes mellitus (T2DM) patients: a critical gender differences analysis. J Res Gender Stud 7: 93–108
- Caruso R et al (2018) Health literacy in type 2 diabetes patients: a systematic review of systematic reviews. Acta Diabetol 55: 1–12
- Coyne JC, Smith DA (1991) Couples coping with a myocardial infarction: a contextual perspective on wives' distress. J Pers Soc Psychol 61: 404–12
- Crowe M et al (2015) Conducting qualitative research in mental health: thematic and content analyses. Aust N Z J Psychiatry **49**: 616–23
- Franks MM et al (2006) Spouses' provision of health-related support and control to patients participating in cardiac rehabilitation. J Fam Psychol 20: 311–8
- Franks MM et al (2010) Diabetes distress and depressive symptoms: a dyadic investigation of older patients and their spouses. *Family Relations* 59: 599–610
- Gibson TB et al (2010) Cost sharing, adherence, and health outcomes in patients with diabetes. *Am J Manag Care* **16**: 589–600
- Ha NT et al (2017) Stratification strategy for evaluating the influence of diabetes complication severity index on the risk of hospitalization: a record linkage data in Western Australia. J Diabetes Complications 31: 1175–80
- Iglay K et al (2016) Prevalence and co-prevalence of comorbidities among patients with type 2 diabetes mellitus. *Curr Med Res Opin* 32: 1243–52
- Lallukka T et al (2016) The joint contribution of diabetes and work disability to premature death during working age: a populationbased study in Sweden. *Scand J Public Health* **44**: 580–6
- Lee VYW et al (2016) Managing multiple chronic conditions in Singapore? Exploring the perspectives and experiences of family caregivers of patients with diabetes and end stage renal disease on haemodialysis. *Psychology and Health* **31**: 1220–36
- Lin P-J et al (2015) Multiple chronic conditions in type 2 diabetes mellitus: prevalence and consequences. *Am J Manag Care* **21**: e23–34
- Lister Z et al (2016) Partner expressed emotion and diabetes management among spouses living with type 2 diabetes. *Fam Syst Health* **34**: 424–8
- Martire LM et al (2004) Is it beneficial to involve a family member? A meta-analysis of psychosocial interventions for chronic illness. *Health Psychol* **23**: 599–611
- Morris M et al (2006) Partners' experiences of living with someone with type 1 diabetes. *Journal of Diabetes Nursing* 10: 194–5
   Nash J (2013) Dealing with diagnosis. In: *Diabetes and Wellbeing.*
- Wiley-Blackwell, Oxford: 23–48 Oftedal B et al (2010) Perceived support from healthcare practitioners
- among adults with type 2 diabetes. *J Adv Nurs* **66**: 1500–9 Saunders B et al (2017) Saturation in qualitative research: exploring
- its conceptualization and operationalization. Qual Quant 1–15. https://doi.org/10.1007/s11135-017-0574-8
- Strom JL, Egede LE (2012) The impact of social support on outcomes in adult patients with type 2 diabetes: a systematic review. Curr Diab Rep 12: 769–81
- Tong A et al (2007) Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. Int J Qual Health Care **19**: 349–57
- van Nes F et al (2010) Language differences in qualitative research: is meaning lost in translation? *Eur J Ageing* **7**: 313–6
- van Puffelen AL et al (2014) Living with diabetes: a group-based selfmanagement support programme for T2DM patients in the early phases of illness and their partners, study protocol of a randomised controlled trial. *BMC Health Serv Res* **14**: 144
- Wearden AJ, Tarrier N, Davies R (2000) Partners' expressed emotion and the control and management of type 1 diabetes in adults. J Psychosom Res 49: 125–30
- Zhang H, Wang C, Ren Y et al (2017) A risk-score model for predicting risk of type 2 diabetes mellitus in a rural Chinese adult population: a cohort study with a 6-year follow-up. *Diabetes Metab Res Rev* 33: e2911

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