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Vloga družinskih odnosov v samooskrbi sladkorne bolezni tipa 2 in njihova povezava s psihosocialnimi izidi bolnikov

The role of family relations in the self-care of type 2 diabetes mellitus and their relationship with psychosocial outcomes

Povzetek

V zadnjih petih letih smo priča neverjetnemu napredku v obravnavi bolnika s sladkorno boleznijo tipa 2 (SBT2). Velik del napredka gre pripisati novi farmakološki terapiji, ki poleg tega da uspešno nadzoruje glikemijo, znižuje incidenco srčno-žilnih dogodkov in srčnega popuščanja ter upočasnjuje ledvično odpoved. Kljub temu pa študije opozarjajo, da približno 50 % pacientov s SBT2 še vedno ne dosega svojega ciljnega glikiranega hemoglobina (HbA1c). Poleg slabo urejene glikemije sta pri bolnikih s SBT2 pogosta tudi znižana kakovost življenja in povečan stres, povezan s SBT2. Razlog za to lahko iščemo v dejstvu, da sta uspešna preventiva in samooskrba SBT2, ki temelji na ustrezni dieti, zadostni meri gibanja, rednem jemanju predpisane farmakološke terapije in samonadzoru krvnega sladkorja, v veliki meri povezani s podporo družinskih članov in drugih, bolniku s SBT2 bližnjih oseb. Raziskovalci na tem področju ugotavljajo potrebo po multidisciplinarnem pristopu do bolnikov s SBT2 in njihovih bližnjih. V tim, kjer sodelujejo medicinski strokovnjaki, naj bi se vključevali tudi strokovnjaki s psihosocialnega področja, ti predvsem tam, kjer je zaznati slabše medosebne odnose oziroma slabšo podporo bolniku s SBT2. Namen članka je, po pregledu ustrezne literature, opisati vlogo družinskih odnosov v samooskrbi SBT2 in njihovo povezavo s psihosocialnimi izidi bolnikov s SBT2.

Ključne besede: sladkorna bolezen tipa 2, družinski odnosi, podpora, kakovost življenja

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Abstract

Over the past five years, we have witnessed incredible progress in the management of type 2 diabetes (T2DM) patients. Much of the progress is attributed to new pharmacological therapy that, in addition to successfully controlling glycemia, reduces the incidence of cardiovascular events, heart failure, and slows renal failure. However, studies point out that about 50% of patients with SBT2 still do not reach their target glycemic hemoglobin (HbA1c). In addition to poorly regulated glycaemia, reduced quality of life and increased T2DM-related stress are also common in patients with T2DM. Self-care of T2DM is largely related to the support of family members and other close relatives of a patient with T2DM. Researchers in this area have identified the need for a multidisciplinary approach to patients with T2DM and their close ones. The team of medical experts should also include experts in the psychosocial field, most notably where there is a poorer interpersonal relationship or poor support for a patient with T2DM. The purpose of the article, after reviewing the relevant literature, is to describe the role of family relationships in T2DM self-care and their relation to the psychosocial outcomes of patients with T2DM.

Key words: type 2 diabetes, family relationship, support, quality of life

Extended abstract

The role of family relationships in the self-care of type 2 diabetes and their relation with the psychosocial outcomes of patients

1.

Introduction

In the last five years, we have recorded incredible progress in the treatment of patients with type 2 diabetes mellitus (T2DM) (Marín-Peñalver, Martín-Timón, Sevillano-Collantes, and Cañizo-Gómez, 2016). A great deal of the progress can be attributed to new pharmacological therapy that, in addition to successfully controlling glycemia, also reduces the incidence of cardiovascular events, heart failure, and slows renal decline (Sattar, 2019).

Nevertheless, studies provide compelling evidence that roughly 50% of patients with T2DM still do not reach the desired target levels for glycated haemoglobin (HbA1c) (Badedi et al., 2016; Schmieder et al., 2018).

The explanation can be found in the fact that successful prevention and self-care of T2DM, based on proper diet, adequate exercise, regular

administration of prescribed pharmacological therapy, and self-monitoring of blood sugar, is largely associated with support from family members and other loved ones. (Baig, Benitez, Quinn and Burnet, 2015; Emery, Robins, Salyer and Thurby-Hay, 2019).

Relatives who can act as an important bridge between T2DM patients and medical staff and who can assist patients in accepting and managing the disease are rarely involved in T2DM self-care education. The cause can be traced either to the medical staff in charge of self-care education, who underestimate the role of family members in T2DM self-care, or to the patients themselves, who for various reasons, do not wish for their family to participate in self-care education (Shi et al., 2016).

In addition to poorer self-care, it has been identified that patients with T2DM have a poorer quality of life and increased T2DM-related stress. Studies confirm good interpersonal relationships with loved ones, whether close or extended family members or friends are also associated with a better quality of life and reduced stress, which in turn can lead to successful self-care of T2DM. They directly play an important role in T2DM self-sufficiency (Mayberry, Egede, Wagner, & Osborn, 2015).

The purpose of this review article is to describe the role of family relationships in T2DM self-care and their relationship to patients' psychosocial outcomes, noting that family relationships are not limited to close family members (partners and children) but also to relationships between T2DM patients and all who are close to them (friends, neighbours, co-workers). The concept of self-care, which otherwise covers an appropriate diet, sufficient exercise, taking prescribed therapy, and self-monitoring of blood sugar, in this context also covers possible disease prevention.

2.

The purpose of involving relatives and friends in the self-sufficiency of T2DM

Involving family members in T2DM self-sufficiency is complex. Families of patients with T2DM often face a variety of barriers such as difficulties in sharing T2DM-related knowledge and experience, insufficient T2DM-related family communication, difficulties in accepting changing family roles, often unsuccessful attempts to maintain a sense of normalcy in the daily routine, difficulties in finding ways to support each other, and the fact that common concerns remain unrecognized and unaddressed.

The support of family members for the patient often does not therefore have the desired effect. A multidisciplinary approach to patients and their families

is needed to alleviate self-care concerns and reduce the fear of early and late complications of both the disease itself and the treatment. Such an approach also makes it possible to increase awareness of the severity and extent of the disease and encourages positive motivation for the participation of relatives in the self-care of the T2DM patient. (Grabowski, Andersen, Warming, Ommundsen and Willaing, 2017).

Patients and their relatives often express a lack of awareness of the severity and extent of the disease. They attach different meanings to the disease itself, to its treatment, and above all, to the late complications. This, and the fact that patients may want to deal with the disease as if it is solely their concern and do not wish or are unable to share it with other family members, is an important barrier to self-sufficiency of T2DM (Bennich et al., 2017). Patients with T2DM often deny the importance and severity of the disease in front of loved ones and do not establish open and clear communication. They and their loved ones thus speculate about what others think or experience.

Patients want to manage their disease on their own and prefer drugs rather than non-pharmacological therapy so that there is no need to change roles in the family and to maintain an already established family cohesion (Bennich et al., 2019). Additional new requirements (diet, physical activity, blood sugar control) brought about by chronic disease within the family increase the need for closer connection between individual family members, but which often jeopardize the development of remaining family members (Pate, 2019).

Involving others, both in self-care education and in T2DM self-care, does not end with close family members. Wider society, neighbors, co-workers, and friends can also play an important role in the self-care of a patient with T2DM. Newton-John, Ventura, Mosely, Browne, and Speight (2017) describe four different societal responses to a patient with T2DM: a) disease-related control and b) disease-related support. Patients can experience them either positively or negatively. c) A non-interference response - which can also be perceived as positive if they are not close to the patient or negative if the non-interference is perceived as disinterest, and d) an unintentional undermining response when loved ones want to help but fail.

3. **Supportive and non-supportive involvement of relatives and friends in T2DM self-care**

Patients perceive the involvement of relatives and friends in T2DM self-care as sabotaging, when a relative or other loved one makes it difficult for the patient to successfully self-care, or as obstructive, where a relative or other loved one

wants to help but does so in an inappropriate way. Obstructive involvement of relatives and friends T2DM patients often recognize as harassment or accusation (Mayberry, Harper, & Osborn, 2016).

Supportive cooperation, which is perceived as positive, can be practical, when the patient's loved one actively participates in the purchase and preparation of a healthy diet, adheres to a diet that benefits the patient and their treatment regimen, plans and joins in appropriate physical activity, helps the patient to follow the diet both at social events and while eating in restaurants. Supportive cooperation can also be emotional in nature, where patients are able to experience it as positive if relatives are not overburdened with T2DM and are optimistic. Otherwise, when relatives focus only on the negative sides of the disease, undermine the patient's independence, and refuse to participate in T2DM self-care, it is perceived as negative. Patients with T2DM want an open conversation about the disease and its self-care. Even when the conversation is focused on the complications of the disease or its treatment, patients can still experience this as positive support if the loved one shows understanding and remains calm (Bennich et al., 2017).

In contrast to Western cultures, studies from India reveal that both supportive and non-supportive participation of patients' relatives in self-care is associated with improved glycemic control (Ravi, Kumar, & Gopichandran, 2018). This can be explained by the fact that in their culture, any attention from the patient's loved ones has a motivating effect on T2DM self-care.

How successful the participation of patients' partners in self-care will be can be predicted based on an assessment of interpersonal relationships between the patient and their partner. Low levels of family stress, the adjustment in partnership, and positive support perceived by patients predict blood sugar self-monitoring and drug adherence and better adherence to dietary recommendations (Pereira, Pedras, Ferreira, and Machado, 2019). Better relationships between partners weaken the negative link between the economic burden and T2DM self-sufficiency (Novak et al., 2017).

4.

Assessment of the participation of relatives and friends in self-care T2DM

To assess participation in T2DM self-sufficiency, a questionnaire FIAD (Family and Friend Involvement in Adults Diabetes) was developed and verified. Both supportive and non-supportive participation of relatives and friends has been independently associated with overall self-care, blood sugar measurement, diet, and regularity of medication.

Non-supportive participation is associated with higher glycated hemoglobin viewed cross-sectionally, and deterioration in glycemic control. However, this is not related to less frequent blood sugar measurements alone, thus the reason for this is probably elsewhere, possibly in higher T2DM related stress or lower motivation to achieve glycemic control (Mayberry, Berg, Greevy, & Wallston, 2019).

Regardless of the evidence that family functioning and social support are associated with glycemic control (Odume, Ofoegbu, Aniwada, & Okechukwu, 2015; Osuji et al., 2018) and greater drug adherence (Waari, Mutai, & Gikunju, 2018), the opinion of patients with T2DM on the involvement of relatives and friends in self-care education or self-care is not uniform. They see the benefits of involving their loved ones primarily as an aid in purchasing and preparing a healthy diet and participating in physical activity.

Such involvement could prevent or delay the onset of the disease in relatives who are more prone to becoming ill themselves because of a genetic predisposition and the lifestyle they share with the patients. On the other hand, patients have concerns about the involvement of relatives in the self-care of their T2DM, as they feel that the disease is solely their concern and do not see the point, nor do they have the desire to burden the family with their disease.

When relatives and friends are already involved in T2DM self-care, patients wish their involvement to be concrete, e.g. by participating in the preparation of a healthy diet or as an accompaniment to physical activity and not in the form of scolding and reminding what they can and cannot do. Patients expect their loved ones to ask them in what way they want cooperation and support rather than anticipation from loved ones about their needs and wants. Elderly patients with "T2DM-related support" report increased physical activity (McCaskill et al., 2019).

5. **Educating relatives and friends about T2DM self-care**

We can start involving family members in the patient's self-care, as early as the first session of self-care education. It has been shown that family members' involvement with the patient in T2DM self-care improves both biomarkers (HbA1c and BMI) and health-related quality of life (measured by the Short form-36 health questionnaires and QOL questionnaires). (Ebrahimi, Ashrafi, Rudsari, Parsayekta and Haghani, 2018). It was also observed that patients who attended T2DM self-care education with their relatives reported fewer depressive symptoms, more knowledge and better acceptance of T2DM, and greater practical skills required for self-care (Ebrahimi et al., 2018; Shi et al., 2016).

A review of the literature on the involvement of relatives in T2DM self-care education confirmed the above statements also in patients with uncontrolled glycaemia and not only in newly diagnosed patients with T2DM. Regardless of the different interventions - education, different family members involvement in the education, or the duration of the education, it was found that patients with T2DM who undergo self-care education together with family members have better control over their blood sugar and report better psychophysical well-being (Pamungkas, Chamroonsawasdi, and Vatanasomboon, 2017).

It is important that the participation of relatives in self-care education is optional and that the patient's close ones, be they relatives or friends, are involved in self-care of T2DM (Mayberry et al., 2016).

When planning interventions to improve T2DM's self-care, it is necessary to take into account the social conditions in which the patient with T2DM lives, as these significantly affect how, with whom, and where, the patient will be able to attend the education program. In addition to social conditions, it is also necessary to take into account the cultural characteristics of individual families and consequently the roles played by family members (Mayberry et al., 2016).

To improve the family environment in which good self-care support for a patient with T2DM will be possible, a structured approach to working with families has been developed. Family members who participated in the workshops reported more in-depth family relationships, clearer roles, and self-understanding, greater insight into the thinking and concerns of individual family members. They found it easier to identify problematic behaviour and find appropriate possible solutions, and more quickly sought out and acquired new knowledge needed for better self-sufficiency of T2DM (Grabowski, Rodriguez Reino, & Andersen, 2019).

These findings highlight the need for a multidisciplinary approach to T2DM patients and their partners. The team, which includes medical experts, should in cases where there are poorer interpersonal relationships or poorer support for patients with T2DM also include experts from the psychosocial field (Pereira et al., 2019).

6. **Suggestions for the future**

Access to family medical therapy at the primary level is limited both in Slovenia and elsewhere in the world (Marlowe, Hodgson, Lamson, White, and Irons, 2012). One of the limitations is the fact that family therapies are not financed by the Health Insurance Institute of Slovenia. Therefore they present an additional financial burden for families where the family budget already

suffers from other illness related expenses (purchase of medical devices, diet, sick stocks (paid (by employer and Health insurance Institute of Slovenia) time from work) that can lead to job loss).

One option to address the inaccessibility of medical family therapists in the holistic care of patients with T2DM is training medical staff for psychological interventions (Vries et al., 2016; Ismail et al., 2018). However the ineffectiveness of such an intervention may be due to patients' unwillingness to share their psychosocial problems with healthcare professionals from whom they expect only biomedical assistance (Vries et al., 2016).

Another option is the integration of marriage and family therapists into primary care (Marlowe, Hodgson, Lamson, White, & Irons, 2012). In this context, in England, at the primary level, "small family therapy" has found that through pragmatic and eclectic work, family therapists play an important role in dealing with families with relational problems (Smith, Moller, & Vossler, 2017). In Slovenia, primary care is highly developed and accessible (timely, financially, familiar to the patient), where the prevention, diagnosis, and treatment of T2DM is performed under the auspices of a physician, who is a family medicine specialist (Susič, Švab, and Kersnik, 2013).

One of the basic skills that every General Practitioner working as a family medicine specialist must master is a holistic approach with the patient and the use of a bio-psycho-social model taking into account cultural and living dimensions (Kersnik and Švab, 2004). Since the family doctors cannot provide such comprehensive care available in one place on their own, they cooperate with other health and social services. Although the medical family therapists would be beneficial to the established team, they are not covered by the Health Insurance Institute of Slovenia.

7.

Conclusion

Despite the recent availability of newer drugs for the treatment of T2DM, which in addition to acting on glycaemia also reduce the incidence of cardiovascular events, heart failure, and slow the onset of chronic renal failure, a large percentage of patients with T2DM still do not reach the desired target levels for glycaemia. There also remains a high risk of poorer quality of life and T2DM-related stress. Good interpersonal relationships that support the patient in self-care of the disease are an important factor in improving glycaemic control and are positively associated with the psychosocial outcomes of patients with T2DM. To this end, several clinical interventions are available with the aim of improving disease knowledge and interpersonal communication, consequently achieving better

self-care and reducing the psychosocial burden of patients.

The large number of patients with T2DM and their heterogeneity (social, cultural, economic ...) remain a challenge, which cannot be solved by only one type of intervention. It is my belief that a flexible approach with the families of T2DM patients is needed, which will not be associated with high costs and will be accessible in primary care for all patients. This idea also presents the possibility of further research in the field of collaboration between family doctors and marital and family psychotherapists.

Uvod

V zadnjih petih letih smo priča neverjetnemu napredku v obravnavi bolnika s sladkorno boleznijo tipa 2 (SBT2) (Marín-Peñalver, Martín-Timón, Sevilla-Collantes in Cañizo-Gómez, 2016). Velik del napredka gre pripisati novi farmakološki terapiji, ki poleg tega da uspešno nadzoruje glikemijo, znižuje tudi incidenco srčno-žilnih dogodkov in srčnega popuščanja ter upočasnjuje ledvično odpoved (Sattar, 2019). Kljub temu pa študije opozarjajo, da približno 50 % pacientov s SBT2 še vedno ne dosega ciljnega glikiranega hemoglobina (HbA1c) (Badedi idr., 2016; Schmieder idr., 2018) which included a random sample of 288 patients with T2DM proportional to the diabetes population of each primary health care center in Jazan city, Kingdom of Saudi Arabia. Results. More than two-thirds (74%. Razlog za to lahko iščemo v dejstvu, da sta uspešna preventiva in samooskrba SBT2, ki temelji na ustrezni dieti, zadostni meri gibanja, rednem jemanju predpisane farmakološke terapije in samonadzoru krvnega sladkorja, v veliki meri povezani s podporo družinskih članov in drugih, bolniku s SBT2 bližnjih oseb (Baig, Benitez, Quinn in Burnet, 2015; Emery, Robins, Salyer in Thurby-Hay, 2019).

Svojci, ki predstavljajo pomemben most med bolnikom s SBT2 in zdravstvenim osebjem in ki bolnikom lahko pomagajo pri sprejemanju in obvladovanju bolezni, se le redko vključujejo v edukacijo o samooskrbi SBT2 skupaj s svojimi obolelimi družinskimi člani. Vzroke lahko iščemo pri zdravstvenem osebju, zadolženem za edukacijo samooskrbe, ki podcenjuje vlogo družinskih članov pri samooskrbi SBT2, ali pa pri samih bolnikih, ki iz različnih razlogov ne želijo njihovega sodelovanja pri samooskrbi (Shi idr., 2016).

Poleg slabše samooskrbe je za bolnike s SBT2 prepoznano, da imajo slabšo kakovost življenja in povečan stres, povezan s SBT2. Raziskave potrjujejo, da so dobri medosebni odnosi, ki jih ima bolnik s svojimi bližnjimi, naj so to ožji ali širši družinski člani ali prijatelji, povezani tudi z boljšo kakovostjo življenja in zmanjšanim stresom, ta pa z uspešno samooskrbo SBT2, tako da ti posredno ali neposredno lahko odigrajo pomembno vlogo pri samooskrbi SBT2 (Mayberry, Egede, Wagner in Osborn, 2015).

Namen tega preglednega članka je opisati vlogo družinskih odnosov v samooskrbi SBT2 in njihovo povezavo s psihosocialnimi izidi bolnikov, s pripombo, da družinski odnosi niso omejeni samo na ožje družinske člane (partnerji in otroci), temveč tudi na odnose med bolnikom s SBT2 in z vsemi, ki so mu blizu (prijatelji, sosedje, sodelavci). Pojem samooskrbe, ki sicer zajema ustrezno dieto, zadostno mero gibanja, jemanje predpisane terapije in samonadzor krvnega sladkorja, v tem kontekstu zaobsega tudi morebitno preventivo bolezni.

Namen vključevanja svojcev in prijateljev v samooskrbo SBT2

Vključevanje družinskih članov v samooskrbo SBT2 je kompleksne narave. Družine bolnikov s SBT2 se pogosto soočajo z različnimi ovirami. Prepoznane so težave pri medsebojnem deljenju s SBT2 povezanega znanja in izkušenj, nezadostna družinska komunikacija, povezana s SBT2, težave pri sprejemanju spremenjenih družinskih vlog, pogosto izjalovljeni poskusi obdržati v vsakdanji rutini občutek normalnosti, težave pri iskanju načinov, kako podpreti drug drugega, ter dejstvo, da skupne skrbi ostanejo neprepoznane in nenaslovljene. Zato podpora družinskih članov obolemu pogosto nima želenih učinkov. Z namenom preprečiti skrbi, povezane s samooskrbo, in zmanjšati strah pred zgodnjimi in poznimi posledicami tako same bolezni kot tudi zdravljenja, je potreben multidisciplinarni pristop do bolnikov in njihovih družin. Tak pristop omogoča tudi povečanje zavedanja o teži in obsežnosti bolezni ter spodbudi pozitivno motivacijo za sodelovanje svojcev pri samooskrbi obolelega s SBT2 (Grabowski, Andersen, Varming, Ommundsen in Willaing, 2017).

Bolniki in njihovi svojci velikokrat izražajo pomanjkljivo zavedanje o teži in obsežnosti bolezni. Sami bolezni, njenemu zdravljenju in predvsem poznim posledicam pripisujejo različne pomene. To in pa dejstvo, da bolniki lahko doživljajo bolezen, kot da je ta samo njihova skrb, in je ne želijo ali ne zmorejo deliti s preostalimi družinskimi člani, predstavljajo pomembno oviro za družinsko preventivo v primeru SBT2 (Bennich idr., 2017). Bolniki s SBT2 pred bližnjimi pogosto zanikajo pomembnost in resnost bolezni ter ne vzpostavijo odprte komunikacije. Ti bolniki in njihovi bližnji tako ugibajo o tem, kaj drugi misli ali doživlja. Bolniki želijo svojo bolezen obvladovati sami in se raje odločajo za medikamentozno kot nefarmakološko terapijo, zato da ni treba spreminjati vlog v družini in da vzdržujejo že vzpostavljeno družinsko povezanost (Bennich idr., 2019). Dodatne nove zahteve (dieta, telesna aktivnost, nadzor nad krvnim sladkorjem), ki jih prinese kronična bolezen v družino, namreč povečajo potrebo po povezanosti med posameznimi družinskimi člani, kar pogosto ogrozi razvoj drugih družinskih članov (Pate, 2019).

Vključevanje drugih, tako v edukacijo samooskrbe kot v samooskrbo SBT2, se ne konča pri ožjih družinskih članih. Tudi širša družba, sosedje, sodelavci in prijatelji, lahko ima pri samooskrbi bolnika s SBT2 pomembno vlogo. Newton-John, Ventura, Mosely, Browne in Speight (2017) opisujejo štiri različne odzive družbe na bolnika s SBT2: a) z boleznijo povezan nadzor, b) z boleznijo povezana podpora, ki ju oba bolnik lahko doživlja pozitivno ali negativno, c) odziv nevmešavanja, ki je prav tako lahko doživet kot pozitiven, če si z bolnikom nista blizu,

ali pa negativno, če je nevmešavanje doživeto kot nezainteresiranost, in d) odziv nenamerne spodbujanja, ko bližnji sicer želijo pomagati, vendar so pri tem neuspešni.

3. **Podporno in nepodporno vključevanje svojcev in prijateljev v samooskrbo SBT2**

Podporo svojcev in prijateljev pri samooskrbi SBT2 bolniki doživljajo tako negativno kot obstruktivno, kadar svojci ali drugi bližnji s svojimi dejanji bolniku otežujejo uspešno samooskrbo SBT2, ali kot izjalovljeno, kadar svojci ali drugi bližnji želijo pomagati, vendar to naredijo na neustrezen način, ki ga bolnik s SBT2 razume kot nerganje ali obtoževanje (Mayberry, Harper in Osborn, 2016).

Podporno sodelovanje, ki je doživeto kot pozitivno, je lahko praktične narave, ko bolnikov bližnji aktivno sodeluje pri nakupu in pripravi zdrave prehrane, se drži urnika prehranjevanja, ki je v korist bolniku in njegovemu režimu zdravljenja, skupaj z bolnikom načrtuje in izvaja ustrezno telesno dejavnost in bolniku pomaga pri upoštevanju diete tudi na družabnih dogodkih ter pri prehranjevanju v restavracijah. Podpora je lahko tudi čustvene narave in jo bolniki doživljajo kot pozitivno, kadar se svojci ne obremenjujejo pretirano s SBT2 in so optimistično naravnani. V nasprotnem primeru, ko se svojci osredotočijo samo na negativne strani bolezni, rušijo bolnikovo samostojnost in odklonijo sodelovanje pri samooskrbi SBT2, je pomoč zaznana kot negativna. Bolniki s SBT2 si želijo odprt pogovor o bolezni in njeni samooskrbi. Kadar je pogovor nanesel na zaplete bolezni oziroma zdravljenja bolezni, so bolniki doživeli komunikacijo pozitivno podporno, če je bližnji izkazal razumevanje in ostal miren (Bennich idr., 2017).

Za razliko od zahodnih kultur v Indiji ugotavljajo, da je tako podporno kot nepodporno sodelovanje bolnikovih bližnjih pri samooskrbi povezano z izboljšanjem urejenosti glikemije (Ravi, Kumar in Gopichandran, 2018), kar si lahko razlagamo tudi tako, da v tej kulturi vsaka pozornost bolnikovih bližnjih deluje motivacijsko.

Kako uspešno bo sodelovanje partnerjev obolelih pri samooskrbi, je mogoče napovedati na podlagi ocene posameznih medosebnih odnosov tako pri partnerjih obolelih kot tudi pri bolnikih s SBT2. Stres v družini, prilagoditev v partnerskem odnosu in pozitivna podpora, ki jih zaznamo pri bolnikih, napovejo samonadzor krvnega sladkorja in redno jemanje predpisane terapije, prilagoditev v partnerskem odnosu in pozitivna podpora, zaznani pri partnerjih, pa prav tako napovejo uspešen samonadzor krvnega sladkorja ter upoštevanje dietnih priporočil (Pereira, Pedras, Ferreira in Machado, 2019). Boljši odnosi med

partnerjema oslabijo negativno povezavo med ekonomskim bremenom in samooskrbo SBT2 (Novak idr., 2017).

4. **Ocena sodelovanja svojcev in prijateljev v samooskrbi SBT2**

Za oceno sodelovanja pri samooskrbi SBT2 je bil razvit in preverjen vprašalnik, ang. FIAD (*Family and Friend Involvement in Adults Diabetes*). Izkazalo se je, da se tako podporno kot nepodporno sodelovanje svojcev in prijateljev neodvisno povezuje s celotno samooskrbo, merjenjem krvnega sladkorja, dieto in rednostjo jemanja zdravil. Nepodporno sodelovanje pa je povezano z višjim HbA1c, gledano presečno, in s poslabšanjem urejenosti glikemije. To sicer ni povezano z manj pogostimi samomeritvami krvnega sladkorja, tako da je verjetno razlog za to drugje, lahko v večjem stresu, povezanim s SBT2, ali pa z manjšo motivacijo za doseganje urejenosti glikemije (Mayberry, Berg, Greevy in Wallston, 2019).

Ne glede na dokaze, da sta družinsko funkcioniranje in socialna podpora povezana z urejenostjo glikemije (Odume, Ofoegbu, Aniwada in Okechukwu, 2015; Osuji idr., 2018) in večjo adherenco zdravil (Waari, Mutai in Gikunju, 2018) 33.5], medium for 26.2% (95% CI: 21.1, 31.3, mnenje bolnikov s SBT2 o vključevanju svojcev in prijateljev v edukacijo o samooskrbi ali samooskrbo ni poenoteno. Prednosti vključevanja vidijo predvsem kot pomoč pri nakupu in pripravi zdrave prehrane ter sodelovanje pri telesni aktivnosti. Tako vključevanje bi pri svojcih, ki so zaradi genetske nagnjenosti in življenjskega stila, ki ga delijo z obolelimi, bolj podvrženi temu, da tudi sami zbolijo, lahko preprečilo ali odložilo nastanek bolezni. Po drugi strani imajo bolniki pomisleke glede vključevanja svojcev v samooskrbo svoje SBT2, saj menijo, da je bolezen skrb njih samih, in ne vidijo smisla niti nimajo želje obremenjevati družine s svojimi bremenami (bolezni).

V kolikor se svojci in prijatelji že vključujejo v samooskrbo SBT2, si bolniki želijo, da bi bilo to vključevanje konkretno, s sodelovanjem pri pripravi zdrave prehrane ali kot spremstvo pri telesni dejavnosti, ne pa v obliki karanja in opominjanja, kaj smejo in česa ne, samo zato ker so bolniki s SBT2. Tako bolniki pričakujejo od svojih bližnjih, da jih ti vprašajo, na kakšen način si želijo sodelovanja in podpore, ne pa predvidevanja bližnjih o njihovih potrebah in željah. Med drugim se opisuje tudi izraz »s SBT2 povezana podpora« (ang.: *diabetes-related support*); starejši bolniki s SBT2, ki so je bili deležni, poročajo o večji fizični aktivnosti (McCaskill idr., 2019).

5. Edukacija svojcev in prijateljev o samooskrbi SBT2

Z vključevanjem družinskih članov obolelega v samooskrbo SBT2 lahko začnemo že pri prvi edukaciji bolnikov o samooskrbi. V primeru, ko se v edukacijo samooskrbe SBT2 poleg obolelega vključijo še družinski člani, ugotavljajo izboljšanje tako biomarkerjev (HbA1c in ITM) kot z zdravjem povezane kakovosti življenja (merjene z vprašalnikom SF-36 in QOL (Ebrahimi, Ashrafi, Rudsari, Parsayekta in Haghani, 2018) a disease with increasing prevalence, requires comprehensive support from family members to ensure that sufferers are able to perform daily activities. The chronic nature of diabetes and its potential side effects impose high financial costs on patients and families, reduce their quality of life (QOL). Prav tako so opazili, da so bolniki, ki so se edukacije samooskrbe SBT2 udeležili skupaj s svojimi svojci, poročali o manj depresivnih simptomih, o več znanja, boljšem sprejemanju SBT2 in boljših praktičnih veščinah, potrebnih za samooskrbo (Ebrahimi idr., 2018; Shi idr., 2016) a disease with increasing prevalence, requires comprehensive support from family members to ensure that sufferers are able to perform daily activities. The chronic nature of diabetes and its potential side effects impose high financial costs on patients and families, reduce their quality of life (QOL).

Pregled literature s področja vključevanja svojcev v edukacijo samooskrbe SBT2 je potrdil zgornje navedbe tudi pri bolnikih z neurejeno glikemijo in ne samo pri novoodkritih bolnikih s SBT2. Ne glede na različne intervencije – edukacije, različne družinske člane, ki so se vključevali v edukacijo, ali trajanje edukacije – je bilo ugotovljeno, da imajo bolniki s SBT2, ki opravijo edukacijo samooskrbe bolezni skupaj z družinskimi člani, boljši nadzor nad svojim krvnim sladkorjem in poročajo o boljšem psihofizičnem počutju (Pamungkas, Chamronsawasdi in Vatanasomboon, 2017).

Pomembno je, da je sodelovanje svojcev pri edukaciji samooskrbe fakultativno in da se v edukacijo in samooskrbo vključujejo bolnikovi bližnji, naj so ti svojci ali prijatelji (Mayberry idr., 2016).

Pri načrtovanju intervencij za izboljšanje samooskrbe SBT2 je treba upoštevati socialne razmere, v katerih bolnik s SBT2 živi, saj te signifikantno vplivajo na to, kako, s kom in kje se bo bolnik lahko udeležil edukacije. Poleg socialnih razmer je treba upoštevati tudi kulturne značilnosti posameznih družin in posledično vloge, ki jih imajo člani v družinah (Mayberry idr., 2016).

Z namenom izboljšati družinsko okolje, v katerem bo mogoča dobra podpora samooskrbi bolniku s SBT2, je bil razvit strukturiran pristop za delo z družinami. Družinski člani, ki so sodelovali v delavnicah, so poročali o bolj poglobljenih znotrajdružinskih odnosih, bolj jasnih vlogah in samorazumevanju, o večjem

uvidu v razmišljanje in skrbi posameznih družinskih članov. Lažje so identificirali problematično vedenje in našli ustrezne možne rešitve ter hitreje poiskali in usvojili nova znanja, potrebna za boljšo samooskrbo SBT2 (Grabowski, Rodriguez Reino in Andersen, 2019).

Te najdbe izpostavljajo potrebo po multidisciplinarnem pristopu do bolnikov s SBT2 in njihovih partnerjev. V tim, kjer sodelujejo medicinski strokovnjaki, naj bi se vključevali tudi strokovnjaki s psihosocialnega področja, zadnji predvsem tam, kjer je zaznati slabše medosebne odnose oziroma slabšo podporo bolniku s SBT2 (Pereira idr., 2019).

6. Predlogi za prihodnost

Dostop do medicinske družinske terapije na primarnem nivoju je tako v Sloveniji kot tudi drugod po svetu omejen (Marlowe, Hodgson, Lamson, White in Irons, 2012). Ena od omejitev je dejstvo, da družinske terapije ne financira Zavod za zdravstveno zavarovanje Slovenije, dodatno finančno breme pa za družine, kjer trpi družinski proračun tudi zaradi bolezni (nakup medicinskih tehničnih pripomočkov in dietne prehrane, bolniški staleži, ki lahko pripeljejo do izgube službe) ni zaželeno.

Eden od poskusov rešitve nedostopnosti medicinskih družinskih terapevtov pri celostni oskrbi bolnikov s SBT2 je dodatno izobraževanje medicinskega osebja za psihološke intervencije (Vries idr., 2016; Ismail idr., 2018), kar pa se ni izkazalo za učinkovito. Vzrok za neučinkovitost take intervencije je lahko tudi dejstvo, da bolniki s SBT2 niso pripravljeni deliti svojih psihosocialnih problemov z zdravstvenim osebjem, od katerega pričakujejo le biomedicinski nadzor (Vries idr., 2016).

Druga možnost je integracija zakonskih in družinskih terapevtov v primarno zdravstvo (Marlowe, Hodgson, Lamson, White in Irons, 2012). V tem kontekstu so v Angliji, na primarnem nivoju, z »malo družinsko terapijo« ugotovili, da s pragmatičnim in eklektičnim delom družinski terapevti pomembno sodelujejo pri obravnavi družin z relacijskimi problemi (Smith, Moller in Vossler, 2017).

V Sloveniji je močno razvito in dostopno (časovno, finančno, pacientu dobro poznano) primarno zdravstvo, kjer pod okriljem zdravnika, specialista družinske medicine, potekajo preventiva, diagnosticiranje in zdravljenje SBT2 (Susič, Švab in Kersnik, 2013).

Ena od temeljnih sposobnosti, ki jih mora obvladati vsak zdravnik, specialist družinske medicine, je celostni, holistični pristop do pacienta in uporaba bio- in psihosocialnega modela ob upoštevanju kulturnih in bivanjskih

razsežnostih (Kersnik in Švab, 2004). Ker take celostne oskrbe, dostopne na enem mestu, ne more zagotoviti sam, sodeluje z drugimi zdravstvenimi in socialnimi službami, med katerimi je dobrodošel tudi medicinski družinski terapevt.

7.

Zaključek

Ne glede na to, da so v zadnjem času za zdravljenje SBT2 na voljo novejša zdravila, ki poleg delovanja na glikemijo znižujejo tudi incidenco srčno-žilnih dogodkov in srčno popuščanje ter upočasnjujejo nastanek kronične ledvične odpovedi, še vedno velik odstotek bolnikov s SBT2 ne dosega ciljne glikemije. Prav tako ostaja veliko tveganje za slabšo kakovost življenja in stres, povezan s SBT2. Dobri medsebojni odnosi, ki omogočajo podporo bolniku pri samooskrbi bolezni, so pomemben dejavnik pri izboljšanju urejenosti glikemije in se pozitivno povezujejo s psihosocialnimi izidi bolnikov s SBT2. V ta namen je bilo preizkušenih nekaj kliničnih intervencij, ki so želele izboljšati znanje o bolezni in medsebojno komunikacijo ter tako doseči boljšo samooskrbo in zmanjšati psihosocialno breme bolnikov.

Kot izziv ostaja še vedno veliko število bolnikov s SBT2 in njihova heterogenost (socialna, kulturna, ekonomska ...), ki je samo en tip intervencij ne more rešiti. Zato menim, da je potreben fleksibilen pristop do družin bolnikov s SBT2, ki ne bo povezan z visokimi stroški in bo v primarnem zdravstvu dostopen vsem. Ta ideja predstavlja tudi možnost nadaljnjih raziskav na področju sodelovanja med družinskimi zdravniki in zakonskimi ter družinskimi psihoterapevti.

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