


Self-Care of Adults with Type 2 Diabetes During the COVID-19 Pandemic: A Qualitative Interpretive Description Study

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Abstract

Due to coronavirus disease 2019 (COVID-19), diabetes services have been disrupted, causing difficulties for people with type 2 diabetes mellitus (T2DM), and understanding their experience could help improve diabetes care. Therefore, we used a qualitative interpretive description to explore the experience of self-care of adults with T2DM during the COVID-19 pandemic. Data were collected using semi-structured interviews and analyzed theoretically. The sample ($N=30$) was composed of 7 females and 23 males, with a mean age of 69.9 years (60–77) and 19.4 mean years (3–40) of people living with T2DM. Our findings show reduced physical activity and increased smoking and alcohol consumption affected that self-care. Increased food consumption and stress eating, with greater stress and anxiety, caused worsening of glycemic values. Participants were able to contact healthcare professionals via eHealth or telephone. Others, even those with complications, were not able to receive care or advice. These results suggest that easier contact with health providers, continuous engagement, eHealth solutions, and formal peer support could help self-care in T2DM. Advanced nursing roles and services could solve many issues reported in this study during and after the pandemic.

Keywords

type 2 diabetes, self-care, self-management, COVID-19, qualitative research

Introduction

The novel coronavirus disease 2019 (COVID-19) has been spreading throughout the globe for over two years. At the beginning, the measures to respond to the COVID-19 pandemic included lockdown and social distancing in several countries. Resources were moved to acute and intensive care services while chronic and primary care services, included those for people with type 2 diabetes mellitus (T2DM; Forde et al., 2021), were reduced or disrupted (Beran et al., 2021). COVID-19 might be especially challenging for people with T2DM, as having the latter increases the risk of severe cases of SARS-CoV-2 infections (Lim et al., 2021). Furthermore, people with T2DM require several different activities to promote their health and manage their disease, such as physical activity, a balanced diet, regular check-ups, adherence to medications, procurement of food, drugs, and devices, which are referred to as self-care (Ausili et al., 2018; Luciani et al., 2021; Riegel et al., 2012). COVID-19-related restrictions affected lifestyle and access to care for those with T2DM (Forde et al., 2021; Hall et al., 2021; Wake et al., 2020). Therefore, we can argue that COVID-19 created additional barriers to self-care for people with T2DM.

Self-care is key for people with T2DM, as it can improve glycemic control (Fabrizi et al., 2020) and decrease complications. Self-care is defined by the middle range theory of self-care of chronic illness as the “process of maintaining health through health promoting practices and managing illness” (Riegel et al., 2012). Self-care has three components: self-care maintenance or those behaviors aimed at maintaining the best possible health status; self-care monitoring, those behaviors linked to the recognition of body changes; and self-care management, those behaviors aimed at responding to said changes (Riegel et al., 2012). In T2DM, self-care maintenance includes those behaviors around diet, physical activity, avoidance of alcohol and tobacco, oral and foot care, and adherence to medications and check-ups. Self-care monitoring comprises monitoring of blood sugar values, weight,

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blood pressure, foot conditions, and signs and symptoms of hypoglycemia and hyperglycemia. Self-care management comprises behaviors aimed at managing said signs and symptoms, such as adjusting sugar intake, physical activity, or medicines (Ausili et al., 2018).

Self-care is influenced by clinical, psychological, and social factors (Luciani et al., 2021; Riegel et al., 2012); therefore, it can be hypothesized by countermeasures and restrictions used during the COVID-19 pandemic, for example, lockdown and isolation, closure of gyms and other health-promoting services, difficulties in procurement, and the redirection of resources toward acute settings. Previous studies were contrasting in describing the effects of COVID-19-related restrictions on glycemic control (Biamonte et al., 2021; Falcetta et al., 2021; Ghosh et al., 2020; Masuda & Tomonaga, 2022; Park et al., 2021; Rastogi et al., 2020), exercise (Ghosh et al., 2020; Masuda & Tomonaga, 2022; Ruiz-Roso et al., 2020; Shi et al., 2020), and food intake (Masuda & Tomonaga, 2022; Ruiz-Roso et al., 2020) on people with T2DM. Furthermore, very few studies have been conducted on the self-care of people with T2DM during COVID-19 (Shi et al., 2020; Silva-Tinoco et al., 2021). Only one qualitative study was conducted on patients with T2DM who were diagnosed with COVID-19 and interviewed during medical isolation after discharge from an acute hospital in China (Shi et al., 2020). Thus, the experience of self-care of people with T2DM during the COVID pandemic remains unexplored. Having this information could help professionals understand the challenges faced by people with T2DM during the pandemic and shape clinical practice toward new approaches to improve diabetes care services during and after the COVID-19 pandemic. Therefore, the aim of this study was to explore and describe the experience of self-care of people with T2DM during the COVID-19 pandemic.

Methods

The current study utilized an interpretive description approach (Thorne, 2016). This methodology was chosen due to its closeness to applied practice and its ability to inform decision-making in applied health sciences (Thorne, 2016). Authorizations were obtained from the Institutional Review Boards of the participating centers and the Institutional Review Board of the Diabetes Patients' Association that is active in the region where the study was conducted. The study was conducted in accordance with the Declaration of Helsinki (World Medical Association, 2013), and written or audio-recorded oral informed consent was obtained by all study participants before commencing the study procedures.

Sample

Participants were purposefully sampled according to age, gender, age of living with T2DM, and therapy. Sampling strategy was twofold. On the one hand, patients who were already involved in an ongoing study and who already

signed an informed consent where they gave availability for future interviews were invited to participate. On the other hand, participants were recruited through snowballing via the Diabetes Patients' Association of the province of Milan, Lombardy, Italy. Inclusion criteria were having a confirmed diagnosis of T2DM (American Diabetes Association, 2020) for at least 1 year and being able to participate in a telephone interview in Italian. Exclusion criteria were being unable to provide informed consent and having a diagnosis of neurodegenerative or psychiatric illness or any other condition that could affect the study interviews, for example the inability to speak on the phone or lack of memory of previous events.

Setting

All of the participants were living in Lombardy, Italy, at the time of the interview, the Italian region with the most cases of COVID-19 (Consolandi, 2021). Three phases of the pandemic were identified during data collection, differentiated by the restrictions in force: 9 March 2020—3 May 2020 (Phase I: total lockdown, leaving the house allowed only for essential reasons), May—October 2020 (Phase II: no or almost no restrictions, mask required only indoors), and 6 November 2020—23 April 2021 (Phase III: very strict restrictions, Lombardy was a "red zone": only essential shops were open, curfew from 10 PM to 5 AM, middle and high school and universities were online).

Data Collection

We collected data using a semi-structured interview. We developed the interview guide informed by the middle range theory of self-care of chronic illness (Riegel et al., 2012) and available literature on self-care in T2DM (Fabrizi et al., 2020; Luciani et al., 2021), informal discussions with people from patients' associations, and researchers' experience. The main questions of the interview guide were about changes in lifestyle and diabetes since the start of the pandemic, supplies, relationship with the National Health Service, compliance with restrictions imposed during the health emergency, relationship with caregiver, feelings during the pandemic, and information received with respect to COVID-19 and diabetes. Interviews were conducted by telephone and audio-recorded between May 2020 and February 2021. Participants were interviewed individually and once by nurses they had not had a previous relationship with. The average interview duration was 29.43 minutes (16.20–88.53). Sociodemographic and clinical data were collected using a self-reported online form.

Data Analysis

The data analysis was conducted in accordance with the interpretive description criteria using theoretical logic and thematic analysis principles (Braun & Clarke, 2006; Thorne,

2016). We partially avoided transcription (Halcomb & Davidson, 2006; Watkins, 2017) by listening to audio files several times. For each interview, we compiled a data extraction table summarizing data on themes defined *ex ante* based on the main questions of the interview, transcribing specific quotes related to the themes, and inserting data and quotes that were not attributable to the aforementioned themes (Watkins, 2017). The tables were also integrated with interviewers' notes and research journals. We used multiple cycles of team-based analysis to analyze single cases, and then we performed an across-cases analysis. Finally, we identified and summarized the main themes and subthemes and developed a thematic map to synthesize the analysis results (Sandelowski & Leeman, 2012; Thorne, 2016).

Rigor

The rigor of the current study was ensured mainly by methodological congruence between objective, design, sampling, data collection, and analysis and the use of a self-care theoretical framework (Morse, 2015; Thorne, 2020). To ensure validity and reliability, the analysis was team based, with prolonged engagement and peer debriefing, and the meetings and critical discussion among the broader team acted as a miniature audit (Morse, 2015). In Qualitative Applied Health Research, saturation is deemed incompatible with the ontology of the discipline and object and of the inquiry (Thorne, 2020). Instead, our methodological choices were guided by principles of coherence and credibility and aimed at producing a detailed, in depth, and meaningful report of the phenomenon in study, which could be relevant to clinical practitioners and further advance knowledge (Morse, 2015; Thorne, 2020). Last, we adhered to the principles of community involvement and credibility of results and their importance (Yardley, 2000) by involving a patients' association when designing the study and the interview guide and recruiting participants.

Results

A total of 30 people participated in the study, seven of whom were females, with a mean age of 69.9 years (60–77) and 19.4 mean years (3–40) of people living with T2DM (Table 1). Five themes were developed around the experiences of self-care during the pandemic: changes in diabetes, difficulty in accessing supplies, relationship with the health-care system, relationship with the caregiver, and information retrieval (Figure 1).

Changes in Diabetes

Changes in diabetes related to the COVID-19 pandemic were ubiquitous among our participants. The main change linked to restrictions of the first and third phases was the reduction or complete suspension of physical activity, as many

participants engaged in movement or sport regularly (running, walking, dancing, cycling, etc.), as this woman explained: "I used to go to the gym twice a week for postural gymnastics, and now the gym is closed. I tried and did movement in the garden or around the house" (F, 73 years). The restrictions led participants to engage in different activities, either more rudimentary, such as moving around the house or doing stairs, or more structured, such as the stationary bike or even creating a small gym in the house. The lack or reduction of physical activity induced many participants to develop strategies to compensate and maintain glycemic values in range, both with adjustments in the therapy and in the diet.

Since I could move less, I reduced my carbohydrates. My diet was already very low in carbohydrates, but I now have eliminated bread, pasta and rice. This allowed me to eliminate some hypoglycemic drugs and to significantly decrease insulin units. (M, 63 years)

For some, staying at home was an occasion to control more and put more attention on the diet and the food that was more difficult to do while working. For others, staying at home led to an increase in food intake, deterioration in the quality of food consumed, for example, by eating foods not included in a diabetic diet, and stress eating.

You get more gluttonous because you're in the house with the lockdown and you could not go out and knowing that in the house maybe there is something to put in your mouth, you start gnawing, eating something you should not eat. (M, 62 years)

In addition, there was an increase in alcohol and tobacco consumption among the participants, with some even beginning to drink alcohol during lockdown periods. Among smokers, some managed to keep the number of cigarettes smoked daily stable, but most disclosed smoking more. All of these factors led in some cases to weight gain, which affected 5 of the 30 participants, one of whom reported gaining 20 kg since the start of the pandemic. Another consequence was glycemic decompensation. Changes in glycemic values, often increased, were a common factor for many participants. The causes are not always known and clearly identifiable by participants. Increased sedentary lifestyle and dietary changes were decisive factors, but stress and worries also played a significant role, as reported by this participant:

It was a total breakdown. [Glycemic values were] either too low or too high, it was some trouble. Blood sugar is a stressor. As I usually have it too high because I am a worried and anxious person. In addition, this led me to a decompensation. (F, 73 years)

Among the sample, several emotions were reported: anxiety, stress, fear, sadness, nervousness, discomfort, worry, boredom, indifference, or lack of meaningful events. One of the predominant feelings was the fear of contracting the virus

Table 1. Sociodemographic and Clinical Characteristics of the Sample (N = 30).

| | |
|--|-----------|
| Age | Years |
| Range | 60–77 |
| Median age | 71 |
| Mean age | 69.9 |
| Sex | N (%) |
| Female | 7 (23.3) |
| Male | 23 (76.7) |
| Living with someone | N (%) |
| No | 1 (3.3) |
| Yes* | 29 (96.7) |
| Partner | 27 (93.1) |
| Son or daughter | 8 (27.6) |
| Son-in-law or daughter-in-law | 1 (3.4) |
| Occupation | N (%) |
| Retired | 22 (73.3) |
| Unemployed | 1 (3.3) |
| Homeworker | 2 (6.7) |
| Working | 5 (16.7) |
| Presence of caregiver | N (%) |
| No | 26 (86.7) |
| Yes | 4 (13.3) |
| Living with caregiver | 4 (13.3) |
| Years from T2DM diagnosis | Years |
| Range | 3–40 |
| Median | 18 |
| Mean | 19.4 |
| Treatment for diabetes* | N (%) |
| Diet | 18 (60) |
| Oral hypoglycemic drugs | 26 (76.7) |
| Injectable hypoglycemic drugs (noninsulin) | 3 (10) |
| Insulin | 13 (43.3) |
| T2DM provider | N (%) |
| Hospital diabetologist | 4 (13.3) |
| General practitioner | 26 (86.7) |

*Multiple answers possible.
T2DM = type 2 diabetes mellitus.

and the stress generated by the emergency situation, also because having diabetes was a risk factor for complications in COVID-19 and the awareness of being a fragile subject was a source of concern for many participants. Mood also had an impact on the participants' sleep. Many reported a worsening of sleep since the pandemic began: difficulty getting to sleep, waking up at night and inability to fall back to sleep, and fewer hours of sleep. Some have tried natural remedies, while others have started taking medication, but in both cases, the results have not been satisfactory. The worsening of sleep led, in some cases, to a rise in glycemic values: "Those moments when I was analyzing all the problems, all the jobs that stopped, even the lack of income, in those circumstances led me to sleep a little less and the glycemic values were altered, they rose" (M, 72 years). In contrast,

those who did not record significant changes in their state of mind reported an increase in the amount of sleep and rest: "I must say that I slept more because I had nothing to do" (M, 71 years). In response to changes in glycemic values, some participants increased the frequency of glycemic checks from once a week to once a day or changed the time of the checks, for example, in the evening, so that they could go to sleep without worries. With respect to drug therapy, the majority of patients (76.7%) were taking oral hypoglycemic drugs and continued to take them despite changes in blood glucose values, while some participants had their therapy changed by their diabetologist. Among participants on insulin therapy, some were able to self-manage their insulin therapy effectively, while others were not able to make their own decisions about drug dosage and therefore had more unstable blood glucose values. One patient faced this problem for the first time during lockdown without being aware of how to manage insulin therapy:

I have always been convinced that if my tooth hurts, I have to go to the dentist, not the greengrocer. It is not like I can just decide on my own to do 30 units, it is not in heaven or on earth. Unless my diabetologist tells me—Mr. Z., look, you can handle it, if you see that it is going up you can do 18 units, if you see that it goes up from 18 you can do 22, or if you see that it goes down you can lower it, but they must always tell me. Until now, until the last visits, this problem did not exist because I managed to stay within the limits, always slightly high, but it was quite manageable. (M, 65 years)

There were also some cases of participants who did not change their habits due to restrictions or health emergencies: "I would say that it did not change at all, I follow the usual routine of checks and self-control, diet and so on, nothing special" (M, 74 years).

Difficulty in Accessing Supplies

The second theme is about the difficulty in accessing supplies of food, drugs, and devices for T2DM. Almost one-third of the sample did not leave the house during the first lockdown because they were afraid of COVID-19. These people managed to get everything they needed thanks to the support of family members or associations and through technology. Shopping was often done by spouses, close relatives, or neighbors. One method of drug procurement used by the majority of the sample since the beginning of the pandemic has been electronic prescriptions. In some cases, the participants were able to manage these themselves and found them very useful to avoid going out. However, the use of electronic prescriptions was not immediate for some people, especially the older ones, and not everyone in the sample had a computer or a smartphone, knew how to use it, or had someone close to them who could. The use of technology was thus found to be a double-edged sword, with great

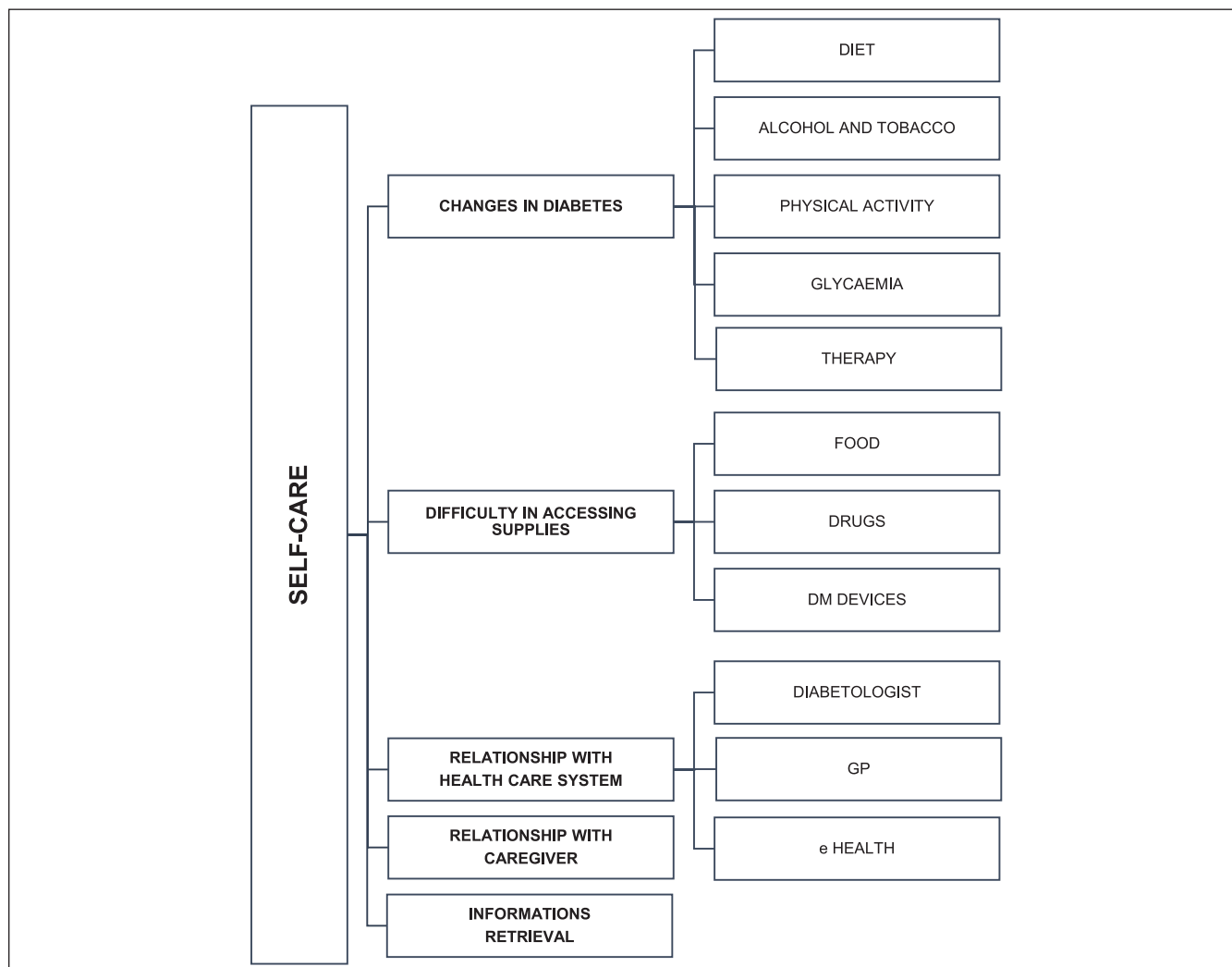


Figure 1. Graphical representation of themes and subthemes.

potential but currently limited to a few able to use it: “I do not know if you’re not used to these things here [technology] how do you do things and manage in this day and age” (M, 76 years). The greatest inconvenience was experienced by participants on insulin therapy, who in some cases saw their health in serious danger due to the unavailability of the drug, for example:

A patient with diabetes ran out of insulin, the pharmacy was closed, and his GP had COVID. The region intervened, indicating another GP who could prescribe it for him. Another person had not had insulin for four days because the hospital center where they usually went to get it was closed. Their partner called me, and fortunately, one member [of the association] lent him his insulin. (F, 73 years)

As in the case of medication, the procurement of diabetes devices (needles, syringes, lancets, lancing devices and strips, and glucometers) was hindered by organizational obstacles. Among these, an insufficient number of glucometer test strips are available for each person per month. One

participant had to autonomously obtain the necessary test strips for adequate monitoring of the blood glucose profile:

I am entitled to 25 blood glucose strips for three months, which would mean measuring my blood glucose more or less twice a week. However, now that I was not going out it was not enough for me. So I bought the strips on the internet, and now I have about one check every day. (M, 76 years)

However, one strategy that allowed people to live the lockdown period with more serenity was to have a stockpile of devices at home to use in case of emergency. “Periodically, because I always go to the same pharmacy, when the equipment is about to run out, before it runs out, I stock up and so I always have everything at home” (M, 72 years).

The Relationship with the Healthcare System

The third theme is the relationship with the healthcare system. Some of the critical points that we found were the lack of a true point of reference for the treatment of T2DM and its

complications, the superficiality of the examinations and check-ups, the lack of trust in the National Health System as an organization, the lack of a preferential channel for people with diabetes, and the lack of education for people with T2DM. First, it is significant to note that the entire care pathway of diabetic patients in the context of the study is built on a physician-centric idea, and nurses are almost absent, especially in regard to a global assessment and management of the patient and provision of education. However, except for some practical aspects where nurses intervene, such as medications of the diabetic foot, we found from the interviews that there are only two points of reference in the treatment of diabetes: the diabetologist or the general practitioner (GP). Diabetologists work within a Specialist Diabetes Service, but during the first phase of the pandemic, these services were closed, which raised several problems over time. The first is that all patients had their routine diabetological visits canceled, often without being able to reschedule them. Some were rescheduled for the summer or autumn and then carried out. For some of these participants, the only inconvenience was the delay of the visits, but once they had been rescheduled, no further problems were encountered. Others scheduled their appointments in the following months, without the certainty of being able to actually attend them. Others were still unable to attend the visit more than a year later due to problems with the organization of diabetes services:

In March [2020], they phoned me and said that the appointment was canceled; then, no one contacted me again. I got in touch, and they said, “No, the prescription has expired”—because you know it lasts a year. So I could not get a new prescription from an ophthalmologist because he was unreachable. I went to the hospital in [town] to make the appointment, and they would not let me in: “You have to make the appointment on this number”—I called the number, and no one answered! It was disorganized. As a result, I had my last appointment in mid-2019, and it is now 2021, and no one has yet been able to make the appointment. (M, 73 years)

The closure of the usual referral centers has put many people in serious difficulty. Some participants had to resort to private health care not only for check-ups but also for the management of complications. Within the sample, many patients said they felt lost: “What is missing is a preferential channel for certain types of illnesses, for the security of the patients but also to avoid all these delays” (M, 61 years). The lack of a preferential channel for chronic diseases was also obvious in the total lack of a reference point to contact in case of need. For example, several participants tried to contact the diabetologist or the referral center without success, as the centers were closed and there was no other way to get in touch with the specialists or a referral professional. This was reported by many participants and by all those who experienced more or less serious problems during the health emergency. Complications were thus partly a consequence of the suspension of diabetes services in the first phase of the

pandemic and the disorganization or partial closure in the subsequent phases. One participant stated that hospitals do not do enough for people like them with serious illnesses other than COVID-19 and that the elderly were being unfairly sidelined. Some patients report a lack of care for and involvement of the chronically ill, as well as a low quality of care (shorter and shorter visiting times, different diabetologist at each visit with a lack of continuity of care, inability to identify and respond to people’s needs, a fragmented view of the patient). In some cases, the distance between the participants and the diabetologist was so much that they did not even know the name of their physician. In general, we found a certain mistrust toward the National Health System and the care pathways currently reserved for patients with T2DM. In fact, they have not proven able to cope efficiently and safely with emergency situations, although months have passed since the outbreak of COVID-19. In addition, some patients with T2DM are referred to GPs. One participant who has been followed by the GP for 2 years defines himself as “self-taught.” For him, there were no significant changes in the care he received during the pandemic, as he felt he had not been adequately looked after before:

To find yourself in a visit to be told—you do not need to be followed up anymore yearly. . .with all the things. . .see your [general] doctor - well, it annoyed me a little bit, because it is not that someone who’s just barely in the values, I will not say good, but above a little bit the minimum. . .enough, you do not have to follow him. [. . .] Two years ago, I never went to see a diabetologist again, I am self-taught [. . .] I do my own check-ups, I know that every year I have to have eye tests and blood tests, I go every year, I do them myself, I get the referral from the GP. (M, 62 years)

GPs have become a reference point for diabetes for almost one-third of the sample since the clinics were closed, and many participants were satisfied with their GP and their relationship with him. However, they can manage people with T2DM only when they are stable and compensated; when the situation changes, people need to be referred back to the diabetologist. Despite the efforts of the GPs, many participants expressed the need to find ways to be followed by experts in the field of diabetes even in times of health emergency. EHealth has been useful in the most critical phase; participants reported using phones, apps such WhatsApp, and emails to reach their providers, especially when the visits were being postponed indefinitely, as this participant recalled:

I did the visit via cell phone because with an email we were asked to prepare all the documents, all the documentation that normally the diabetologist sees on the visit, and by phone [the diabetologist] asked us questions and I sent everything via email scans of the various tests, blood tests, cardiologist, and carotid check. It was a “paper” visit like the previous ones, only that we did not see the doctor but they spoke on the phone. In addition, I was relieved because it is like having done the visit. (M, 61 years)

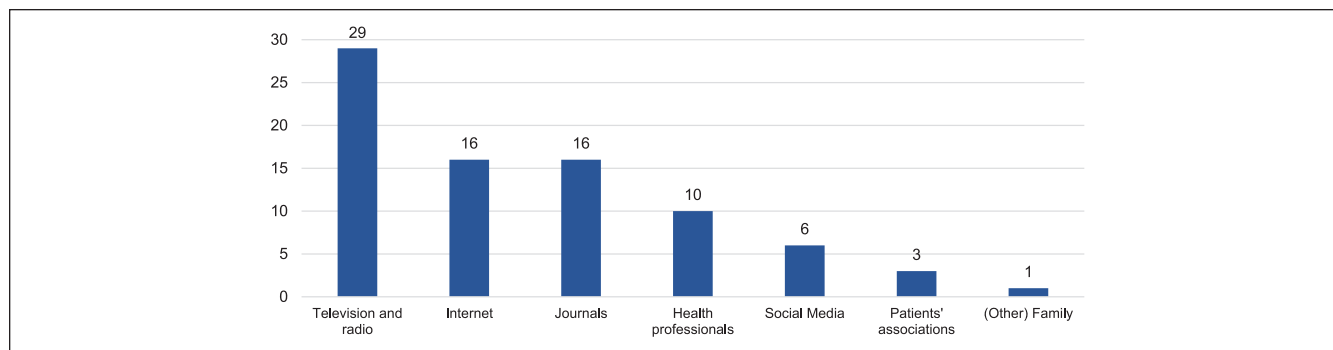


Figure 2. Methods of information retrieval on COVID-19 and diabetes (multiple answers possible) ($N=30$). COVID-19=corona virus 2019.

Not everyone liked being only able to talk with a provider on the phone. Furthermore, similar to the use of electronic prescriptions, eHealth, to work, needs adequate tools and knowledge of technology, which could limit access in some people, as this participant highlights:

A lot of online activities have developed right now in my opinion, which is good. However, there is a small problem: the people who go online are the ones who are more experienced. They have an advantage because of their culture, motivation and desire. Older people, on the other hand, cannot even get online. They cannot, and many do not have computers, cannot see, do not have anyone. There is a segment of the population that needs to be taught. They need to be reached because they are not able to get to the information. Now with eHealth [you could take a significant step forward], if it actually worked well. (F, 73 years)

The Relationship with the Caregiver

The fourth theme is the relationship with the caregiver. The majority of participants described themselves as autonomous in the self-care of their diabetes, without the need for a caregiver. However, 96.7% of the participants are cohabiting (Table 1), and almost all of the sample reported how the physical closeness of another person has been important for material and emotional support. For many, the spouse provided practical help in maintaining an adequate level of self-care, for example, by cooking, offering support and company in physical activity, and reminding them of therapy and appointments. For most of the participants, the relationship with the spouse has not changed since the beginning of the pandemic. For others, the health emergency has been an opportunity to get even closer with their spouse and strengthen their caregiver's contribution, for example, in the diet or in the physical activity. As this participant recalls, since the beginning of the pandemic, his wife has been more attentive to him; for example, when he gets hyperglycemic, his wife makes him dance in the house so that the values can be balanced by physical activity: “[My wife] keeps me in line on eating, she stimulates me on so many things, to walk,

to dance, she pushes me. She's the one who helps me in everything, if I'm here I owe it to her!” (M, 69 years).

Information Retrieval about COVID-19 and T2DM

The last theme is information retrieval about COVID-19 and T2DM. Regarding COVID-19, the entire sample stated that they had received a great deal of information since the beginning of the pandemic. Some participants raised the issue of “too much information” stating that they were overwhelmed by the news and information received. The media used by almost all participants was television due to the large amount of time available at home, along with the Internet, newspapers, and social networks (Figure 2). Most participants, however, found these sources unclear, confusing, and conflicting, and some raised the problem of how to trust information. As stated by this participant, an important factor for information retrieval was the ability of critical thinking, which allowed them to distinguish between reliable news and false news:

The sources did not always seem reliable to me, but frankly, I think I have a minimum of independence of thought and I can understand when a piece of news is well-founded compared to when it is a hoax or false and biased news. (M, 71 years)

This discrimination was not possible for everyone, as declared by one participant who, when asked which source was the most reliable, replied: “Can I say none? It was all chaos. It was all different information. This was very confusing. In addition, it still is” (F, 73 years).

As per information about diabetes, the main source was health professionals, although not all participants had reference points to whom they could ask their questions. Among those who were able to reach their diabetologist or GP, there was greater satisfaction in terms of the information received: “The most reliable [of the sources was] absolutely my diabetologist” (M, 63 years). Those who belonged to some kind of diabetes association had the specialists they worked with as their main source—experienced and trustworthy people. In

contrast, those who did not have a network or the opportunity to contact a diabetes specialist were disappointed by the scarce and reliable information about diabetes, as this participant stated:

Regarding the management of diabetes in relation to the coronavirus period, there was no information. I did not look for it because I'm perfectly capable of managing it autonomously, and I did not expect it because I'm not naïve. Let us say that if there had been more, it would have been better, it would have been a perception of attention that would certainly have improved the state of mind. I'm a seasoned diabetes professional, but I have heard of diabetics, especially newcomers, who, especially at the beginning, found it very difficult to manage from an emotional point of view. So at that moment yes, it would have been a very good support, a psychological support for diabetics, it would have been appropriate, but given how busy the health workers were it seems to me quite pretentious. (M, 63 years)

The more web-savvy participants looked through official sources such as the World Health Organization and the Ministry of Health for reliable information. One patient relied exclusively on medical newsletters and institutional sites such as those of the Italian Society of Diabetology and the Association of Diabetes Physicians. In contrast, some participants reported a passive attitude and disinterest in information, both regarding COVID-19 and diabetes: "Nothing worries me, so I do not ask questions. What they said about diabetes is fine, but I'm not interested in COVID" (M, 69 years).

Discussion

This study aimed to explore and describe the experience of self-care of people with T2DM during the COVID-19 pandemic. Our findings revealed critical aspects regarding the organization of health services for patients with T2DM. In a situation of added complexity due to the COVID-19 pandemic, many participants found themselves having to manage diabetes with minimal or absent support from healthcare providers. Most of the participants reported a worsening of self-care, for example, in a lower level of physical activity, lower adherence to a healthy diet, and increased alcohol and tobacco consumption. Several participants reported that they did not feel cared for by the health system from the beginning of the pandemic, with some extreme cases of people who remained without insulin. Even if some forms of eHealth facilitated the interactions, it remained critical. In addition, the sense of abandonment and the lack of points of reference had important psychological consequences on participants, such as anxiety, stress, and fear, which added up to those triggered by the pandemic. Taken together, these results are extremely relevant, as they suggest the need to improve community care services to support patients with diabetes and, more generally, with chronic conditions both during and after the pandemic.

The worsening of self-care in people with T2DM was hypothesized at the beginning of the pandemic due to the restrictions imposed by it and the prioritization of urgent and high-intensity care to those affected by COVID-19 (Wake et al., 2020). A recent study (Forde et al., 2021) highlighted how people with T2DM had suffered from a severe disruption of diabetes services throughout Europe with less care and education provided. In our study, these disruptions are probably exacerbated because they are occurring in an already fragmented care environment for people with diabetes that did not maintain continuity of care or reliance on a diabetes nurse case manager or family nurse. A diabetes nurse case manager or family nurse—who was not available in the context of the study—could provide care and education, facilitating continuity of care and thus improving self-care in people with T2DM (Ishani et al., 2011; Li et al., 2017), even in complex emergencies such as COVID-19 (Baker et al., 2021).

The use of eHealth was helpful for some of our participants, which is consistent with studies in different contexts that show how eHealth was useful for the care of people with diabetes during the COVID-19 pandemic (Ceriello, 2020; Jendle, 2020; Mader, 2020). However, eHealth is still underdeveloped and was based more on the individual ability and availability of patients and providers rather than being a structured, formalized process. While COVID-19 showed the potential of eHealth, in our sample, there was difficulty in approaching and using eHealth, especially for older patients, as well as a disparity between those who had and did not have access to technology. This is consistent with other studies stating that COVID-19 accentuated inequalities and disparities related to access to and use of technology to facilitate diabetes care (Kerr & Warshaw, 2020; Monaghan & Marks, 2020). We also have to situate these results in the Italian context, where 16.8% of the population has never used the Internet compared to the European mean of 9.4% (Digital Economy Society Index, 2021). Therefore, intervention to develop eHealth needs to be accompanied by progress in digital literacy and the availability of technology to patients and providers.

To be able to cope with the diabetes-related problems resulting from the health emergency, some participants in the sample self-organized in groups when the health service was unable to provide timely responses. For example, they were able to manage emergencies such as lack of insulin or the onset of a diabetic foot, as well as providing moral and psychological support. The topic of mutual support between patients with T2DM during the COVID-19 pandemic is extremely novel, and there are no similar studies in the literature. However, similar experiences before the pandemic showed that people with T2DM in self-help groups had higher empowerment, social inclusion, psychosocial support, and coping strategies (Kofahl, 2019; Nickel et al., 2019). Self-help groups, therefore, could be one strategy for people with T2DM to improve their self-care and overall well-being after the pandemic.

Limitations and Strengths

The sample of the present study was composed of elderly white Italians residing in Lombardy, the majority of which were males. The country where the study was conducted (Italy) has a health model that is based on the principle of health as a fundamental human right and guarantees universal health care to all. All together, these aspects could hinder the transferability of the results, especially to private health-based countries and diverse populations. Furthermore, since almost all participants considered themselves autonomous in self-care, the caregiver role might be under represented. While telephone interviews might have prevented the researcher from capturing certain data, such as the nonverbal language of the interviewees, they made it possible to reach numerous people and to gain in-depth knowledge of the phenomenon under study at a time when an in-person study would not have been possible. Furthermore, no previous studies have explored the experience of diabetes self-care during the pandemic. The process of data collection and analysis was conducted rigorously on the basis of interpretive description (Thorne, 2016), thus ensuring reliable results. Therefore, our findings can be transferable to similar populations and cultural contexts. Finally, having involved a diabetes patients' association was key to designing the study, informing the interview guide, and enrolling participants, assuring the voice and perspective of patients being represented.

Conclusion

Self-care is a key strategy for people with T2DM. We found that adults with T2DM struggled to maintain adequate self-care and to access diabetes services during the pandemic. Although our study was conducted during an unexpected and severe global emergency, lessons can be learned to improve diabetes services both during and after the pandemic. Participants advised for a diabetes point of reference, continuity of care, and patients' engagement. Developing advanced nursing roles and services—currently unavailable in the context of the study—could solve many of the issues reported in this study. Future research should develop and test the effectiveness of those services in people with T2DM to improve diabetes care. Based on our results, easier contact with health providers, continuous engagement, eHealth solutions, and formal peer support should be integrated by future interventions to improve diabetes care.

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