

ORIGINAL ARTICLE

## Self-care and caregiver contribution to self-care in adolescents with type 1 diabetes mellitus: a pilot cross-sectional study

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### Abstract

**Background:** Type 1 diabetes mellitus requires complex skills of self-care that, during adolescence, need to be adapted to continuous major changes. Therefore, adolescents could struggle in performing adequate self-care, with consequences on glycaemic control. Caregivers' contribution to self-care could be useful for reaching health outcomes. Existing studies lacked a theoretical framework, and tools administered for measuring adolescents' self-care and caregivers' contribution to self-care were not theory grounded.

**Aim:** To describe adolescents' self-care and caregiver contribution to self-care within the theoretical framework of the middle-range theory of self-care of chronic illness.

**Methods:** A cross-sectional observational study was conducted enrolling 153 adolescent-caregiver dyads. The Self-Care of Diabetes Inventory (SCODI), including self-care maintenance, monitoring and management, was administered to adolescents. The Caregiver Contribution to Self-Care of Diabetes Inventory (CC-SCODI), including caregiver contribution to self-care maintenance, monitoring and management, was administered to caregivers. We analysed the differences in caregiver contribution according to adolescents' self-care level and the differences in caregiver characteristics according to their contribution to self-care level.

**Results:** Adolescents mostly obtained adequate scores for self-care maintenance (74%), monitoring (52%) and management (58%). Caregivers mostly obtained adequate scores for contribution to self-care maintenance (72%) and monitoring (52%), and almost adequate scores for contribution to self-care management (41%). Scores were consistent within the dyads for self-care monitoring and management: high caregiver contribution when adequate adolescent self-care and vice-versa ( $P < 0.001$ ). Higher caregiver self-efficacy in contributing to patient self-care was associated with higher caregiver contribution to self-care maintenance ( $P = 0.022$ ), monitoring ( $P < 0.001$ ) and management ( $P < 0.001$ ).

**Conclusion:** Caregivers can contribute significantly to the self-care of adolescents with type 1 diabetes. Health professionals could implement interventions aimed at improving caregivers' contribution through enhancing caregiver self-efficacy in contributing to patient self-care. Researchers could deepen the understanding of the relationship between adolescent self-care and caregiver contribution to self-care, as well as the determinants of caregiver contribution to self-care, and its effects on health outcomes.

Keywords: *self-care; type 1 diabetes; caregiver; self-management; adolescence*

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Poor glycaemic control in adolescents with type 1 diabetes mellitus has significant consequences on the onset of microvascular and macrovascular complications and on the risk of developing physical and psychological health problems in adulthood.<sup>1</sup> Therefore, achieving glycaemic targets is crucial to reduce the risk and the severity of these consequences.<sup>2</sup> Due to the complexity of the management of type 1 diabetes, healthcare professionals should pursue a global and multidisciplinary approach,<sup>3,4</sup> by considering educational, psychosocial, behavioural and emotional factors and involving

the patients and their families.<sup>1,4</sup> Thus, promoting self-care in adolescents with type 1 diabetes is key to optimise glycaemic control.<sup>5–7</sup> Self-care is defined as the 'process of maintaining health through health promoting and managing illness', according to the middle-range theory of self-care of chronic illness,<sup>8</sup> and comprises self-care maintenance, self-care monitoring and self-care management.<sup>8</sup> Self-care maintenance concerns behaviours aimed at maintaining physical and emotional stability. Self-care monitoring regards behaviours to recognise changes in the body. Self-care management includes behaviours

implemented when signs or symptoms occur.<sup>8,9</sup> In type 1 diabetes, self-care maintenance consists, for example, of adherence to medications, diet and physical activity recommendations; self-care monitoring means to monitor blood glucose, body weight and symptoms of hypo- or hyperglycaemia; and self-care management refers to manage episodes of hypo- and hyperglycaemia.<sup>10</sup> Self-care is strongly predicted by self-care self-efficacy,<sup>11,12</sup> defined as the confidence in one's ability to perform self-care and persevere despite barriers.<sup>8,10</sup>

Performing self-care can be a challenge for adolescents: complex skills are required,<sup>2,3</sup> and they need to be constantly adapted to major changes that occur.<sup>5,13</sup> Adolescence is a complex transformative time, and factors like puberty and endocrine changes, meal and exercise patterns, adherence to treatment regimens, and risk-taking and hazardous behaviours can complicate self-care in adolescents.<sup>4</sup> Furthermore, the presence and the involvement of an informal caregiver, a family member or a significant other providing unpaid help<sup>10,14,15</sup> are particularly relevant for type 1 diabetes management in adolescence.<sup>4,16,17</sup>

Studies about caregivers in type 1 diabetes have addressed several issues, such as the relevance of the parent-child relationship quality,<sup>18,19</sup> the caregiver autonomy support,<sup>20</sup> the caregiver mental health,<sup>21</sup> quality of life and burden.<sup>16</sup> All these factors were associated with glycaemic control in adolescence.<sup>16,18-21</sup> Furthermore, previous studies about type 1 diabetes in adolescence have assessed caregivers' behaviours<sup>22</sup> and skills.<sup>23</sup> Nevertheless, to the best of our knowledge, the caregiver contribution to self-care in type 1 diabetes has never been placed within a theoretical framework that is coherent with those behaviours required for patients. In the field of self-care research, caregiver contribution was defined as 'the provision of time, effort and support in the behalf of another person who needs to perform self-care'.<sup>24</sup> It was measured in caregivers of patients with heart failure,<sup>24</sup> and this allowed the update of a situation-specific theory<sup>25</sup> and tailoring of interventions aimed to help both patients and their caregivers. This theory<sup>25</sup> began by describing how caregivers' contribution to self-care affects and contributes to self-care. In type 1 diabetes, caregivers' contribution has never been described nor measured with a theoretically grounded tool. Furthermore, it is unknown if there is a causal relationship between caregivers' contribution to self-care and patients' self-care. Evaluating the self-care of adolescents and the contribution to self-care of their caregivers consistently within the same theoretical framework would provide a better understanding of the self-care process of type 1 diabetes. It would be possible to identify specific areas for enhancing self-care behaviours and/or caregiver contribution to achieve health goals. Moreover, we could identify those caregivers who are more in need of support or education to improve their caregivers'

contributions. Lastly, this pilot description will also allow designing larger observational studies aimed to investigate the complex process of self-care and caregiver contribution to self-care in this population

Therefore, this pilot study had as its general objective an initial exploration aimed to<sup>1</sup> describe self-care maintenance, self-care monitoring and self-care management of adolescents with type 1 diabetes;<sup>2</sup> describe caregiver contribution to self-care maintenance, self-care monitoring and self-care management of adolescents with type 1 diabetes;<sup>3</sup> identify caregivers socio-demographic characteristics associated with the level of caregiver contribution to self-care maintenance, self-care monitoring and self-care management.

## Methods

We conducted a single-centre cross-sectional study involving adolescent patients with type 1 diabetes and their caregivers from a referral centre in the north of Italy. The Institutional Review Board of the centre approved the study, and all participants provided written informed consent. The study was conducted according to the ethical principles of the Declaration of Helsinki.<sup>26</sup>

### Sample

We recruited 153 patient-caregiver dyads ( $n = 306$ ) with consecutive sampling during normally scheduled outpatient visits between October and December 2019. For patients, the inclusion criteria were having a diagnosis of type 1 diabetes, being aged between 10 and 18 years, and being in middle or high school. The exclusion criteria were having severe cognitive impairments and/or having learning problems. The adult accompanying the adolescent, in order to be recruited, had to be one of the main caregivers involved in the daily management of the disease.

### Data collection

Demographic and clinical data of each dyad were collected with a self-report questionnaire. To both patient and caregiver, we asked about age, gender, nationality, education attended and composition of the household. To adolescents, through a closed-ended question collection form, we asked about physical activity, years of illness since onset, type of devices used for the administration of insulin and for measuring blood glucose, and the last available glycated haemoglobin value. To caregivers, we asked about diabetes education at the onset and used open questions to further investigate the main activities they perform to contribute to patients' self-care. The answers provided to the open questions were then classified in order to identify categories to be analysed quantitatively.

To evaluate self-care in adolescents, we used the *Self-care of Diabetes Inventory* (SCODI, available at <https://self-care-measures.com/>), a 5-point Likert type, valid and reliable theory-based instrument.<sup>11,27</sup> The SCODI is

composed of three multidimensional scales, namely, self-care maintenance (12 items), self-care monitoring (8 items) and self-care management (9 items).<sup>27</sup> The SCODI is usually administered with an additional scale that measures diabetes self-care self-efficacy (11 items)<sup>11</sup>. The reliability of the SCODI in assessing self-care in type 1 diabetes was estimated by a previous study<sup>27</sup> using the global reliability index for multidimensional scales.<sup>28</sup> It was at least 0.84 in each of the SCODI scales (values  $\geq 0.70$  were considered adequate).<sup>27</sup> To evaluate the caregiver contribution to self-care, we used the *Caregiver Contribution – Self-Care of Diabetes Inventory* (CC-SCODI, available at <https://self-care-measures.com/>). The CC-SCODI is derived from the SCODI and includes the same scales and items, but focused on how often caregivers recommend behaviours to the person they are caring for, or how often they perform the behaviours in their place to support them. The SCODI was tested for validity, reliability and cross-cultural adaptation, and it was used in several studies about self-care of type 1 diabetes and T2DM.<sup>11,29–31</sup> The CC-SCODI testing is currently ongoing. For both instruments, each scale is scored on 100 point, with higher scores indicating higher self-care or higher contribution to self-care.<sup>11</sup> For the SCODI, the suggested cut points of 60 for self-care management and 70 for all the other scales are based on a glycated haemoglobin level  $>7\%$  as outcome of interest.<sup>32</sup> For the CC-SCODI, the cut-point of 70 for all the scales was acquired consistently with the cut-point used by the other tools assessing the caregiver contribution in other chronic conditions and referring to the same theoretical framework.<sup>10,24</sup>

#### Data analysis

Frequencies and percentages were used to describe socio-demographic and clinical characteristics when variables were categorical, and median and quartiles were used when variables were continuous. To describe the differences in caregiver contribution (CC-SCODI), the caregivers' sample was stratified according to the patient score in self-care scales (SCODI) dichotomised as 'adequate' ( $\geq 60$  for SCODI's self-care management,  $\geq 70$  for the other scales) or 'inadequate' ( $< 60$  for SCODI's self-care management,  $< 70$  for the other scales). To investigate the characteristics of caregivers according to their contribution to self-care (CC-SCODI), the caregiver sample was stratified using 70 as the cut-point to identify 'high' ( $\geq 70$ ) or 'low' contribution. Differences were analysed by the Mann-Whitney U test.

## Results

Socio-demographic and clinical data of patients and caregivers are presented in Table 1. Patients were equally

distributed between sexes (48%,  $n = 73$  females), had a median age of 14 years (Q1–Q3: 13–16) and mostly went to high school (63%,  $n = 96$ ). Half of them had been living with type 1 diabetes for at least 5 years, the vast majority used the continuous glucose sensor for glycaemia detection (84%,  $n = 129$ ) and the pen for insulin delivery (77%,  $n = 117$ ), and more than half of them exceeded the recommended glycated haemoglobin value of 7% (54%,  $n = 83$ ).<sup>1</sup> Caregivers were mainly women (73%,  $n = 111$ ) and mothers of the patient (71%,  $n = 108$ ), with a median age of 47 years (Q1–Q3: 43–50). They were mostly employed (77%,  $n = 118$ ), had a high education (high school or university, 78%,  $n = 120$ ), lived with the partner (85%,  $n = 130$ ) and had at least two children (80%,  $n = 123$ ). About caregiving activities, nearly half of the caregivers reported contributing in at least three areas of activities (49%,  $n = 75$ ), and the most frequent of which were 'diet' (58%,  $n = 89$ ), 'decision on boluses' (46%,  $n = 71$ ) and 'control/supervision in type 1 diabetes management' (42%,  $n = 64$ ). The median scores of self-care maintenance, self-care monitoring and self-care management were adequate in patients, and the median scores of caregiver contribution to self-care were adequate for self-care maintenance and self-care monitoring, but inadequate for self-care management (Table 2).

Analysing the caregiver contribution to self-care according to the patient's level of self-care (Fig. 1), the majority of caregivers provided a high contribution to self-care maintenance both when the patient had adequate self-care maintenance (median = 79.17, Q1–Q3: 68.75–87.50) and when the patient had inadequate self-care maintenance (median = 77.08, Q1–Q3: 68.23–85.42). Caregiver contribution to self-care monitoring was higher when the patient had adequate self-care monitoring (median = 76.47, Q1–Q3: 67.65–82.35) and lower when the patient had inadequate self-care monitoring (median = 61.76, Q1–Q3: 50.00–70.59). Likewise, caregiver contribution to self-care management was higher when the patient had adequate self-care management (median = 69.44, Q1–Q3: 61.11–80.56) and lower when the patient had inadequate self-care management (median = 58.33, Q1–Q3: 47.22–72.22).

Table 3 shows caregivers' characteristics comparing caregivers with high and low contributions to self-care maintenance, self-care monitoring and self-care management. Higher scores in caregiver self-efficacy in contributing to patient self-care were seen in those caregivers contributing with a score  $\geq 70$  in all three scales. In caregiver contribution to self-care maintenance and self-care monitoring, the proportion of mothers providing high contribution was greater (80/108 = 74% and 59/108 = 55%, respectively) than the proportion of fathers (29/42 = 69% and 20/42 = 48%, respectively). Assisting the care recipient in sport was more frequent for caregivers with high contribution to self-care management ( $P = 0.017$ ),

*Table 1.* Socio-demographic and clinical variables of patients and caregivers

Variable		Patient	Caregiver
N		153	153
		<b>Median [1st–3rd quartile]</b>	
Age		14 [13–16]	47 [43–50]
		<b>N (%)</b>	
Gender	Female	73 (48)	111 (73)
Nation	Italy	117 (76)	114 (75)
	Other	36 (24)	39 (25)
Occupation	Student	153 (100)	1 (1)
	Employed	0 (0)	118 (77)
	Housewife	0 (0)	16 (10)
	Retired	0 (0)	1 (1)
	Unemployed	0 (0)	17 (11)
School education	Primary school	0 (0)	2 (1)
	Secondary school	57 (37)	31 (20)
	High school	96 (63)	84 (55)
	University	/	36 (24)
Marital status	Married/cohabitant	/	130 (85)
	Separated/divorced	/	18 (12)
	Single/never married	/	4 (3)
	Widower/widow	/	1 (1)
		<b>Median [1st–3rd quartile]</b>	
Number of children		/	2 [2–3]
Years involved in diabetes caregiving		/	5 [2–8]
		<b>N (%)</b>	
Relationship with the patient	Mother	/	108 (71)
	Father	/	42 (27)
	Brother/sister	/	2 (1)
	Grandparent	/	1 (1)
Patient-caregiver cohabitation	Yes	153 (100.0)	/
Caregiving activities*	Control/supervision	/	64 (42)
	Night assistance	/	47 (31)
	Diet	/	89 (58)
	Decision on boluses	/	71 (46)
	Correction of hyper-/hypoglycaemia	/	52 (34)
	Set change	/	41 (27)
	Assistance in sport	/	15 (10)
Number of caregiving activities	0	/	6 (4)
	1	/	31 (20)
	2	/	41 (27)
	3	/	45 (30)
	4	/	20 (13)
	5	/	9 (6)
	6	/	1 (1)
		<b>Median [1st–3rd quartile]</b>	
Years from diagnosis		5 [2–8]	/
		<b>N (%)</b>	
Diabetes education at the onset	Yes	/	153 (100)
Insulin delivery device	Insulin pen	117 (76)	/
	External insulin pump	36 (24)	/

Table 1. (Continued)

Variable		Patient	Caregiver
N		153	153
Blood glucose detection	Finger-pricking	24 (16)	/
	Continuous glucose sensor	129 (84)	/
Sport activity	Yes	105 (69)	/
Familiarity for type 1 diabetes	Yes	18 (12)	/
Autoimmune Thyroiditis	Yes	11 (7)	/
Celiac disease	Yes	6 (4)	/
Autoimmune Gastritis	Yes	2 (1)	/
		<b>Median [1st–3rd quartile]</b>	
HbA1c	(%)	7.2 [6.7–8.0]	/
	mmol/mol	55.00 [50.00–64.00]	

\*More than one answer possible.

Table 2. Patients' scores in SCODI scales and caregivers' scores in CC-SCODI scales.

Variable	Patient	Caregiver
	<b>Median [1st–3rd quartile]</b>	
Self-care maintenance	77.08 [68.75–85.42]	
CC-self-care maintenance		79.17 [68.75–87.50]
Self-care monitoring	70.59 [61.76–76.47]	
CC-self-care monitoring		70.59 [55.88–79.41]
Self-care management	63.89 [52.78–69.44]	
CC-self-care management		66.67 [52.78–77.78]

while contribution in correcting hyper- or hypoglycaemia is more frequent for caregivers with low contribution to self-care management ( $P = 0.017$ ).

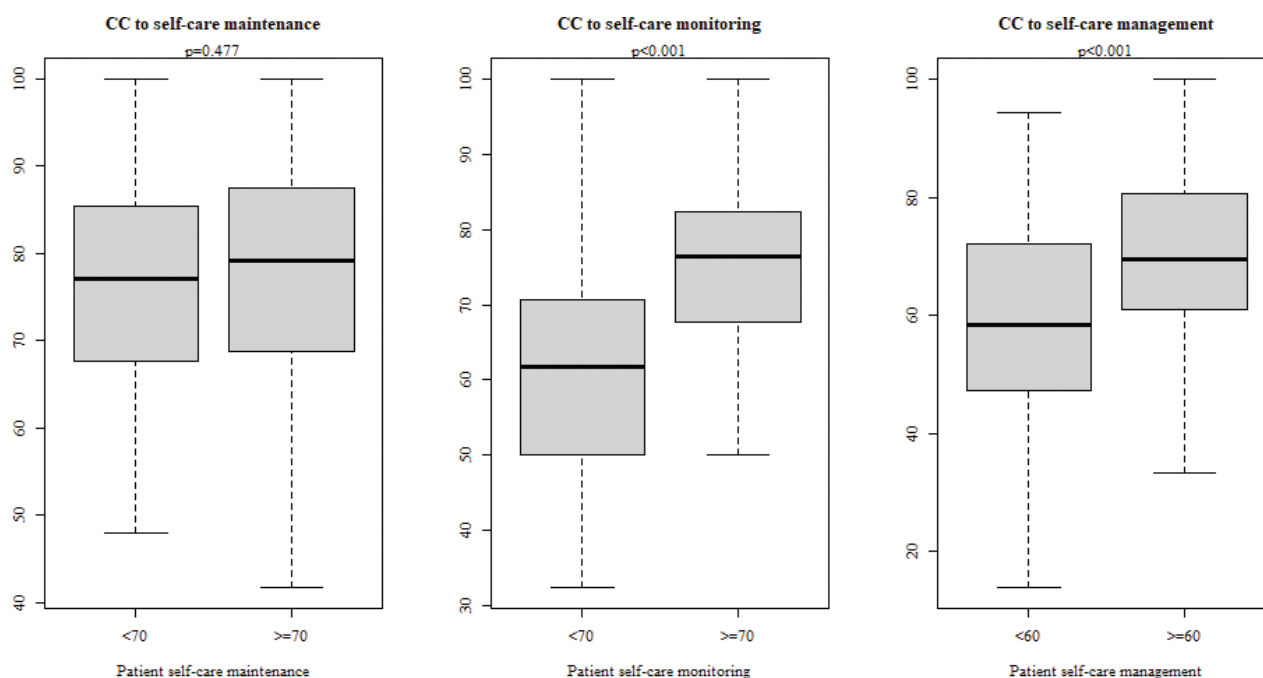
## Discussion

The aim of this study was to describe the self-care of adolescents with type 1 diabetes and caregivers' contribution to self-care measured by theoretically grounded tools. Furthermore, the study aimed to outline the main characteristics of caregivers based on their level of contribution to self-care. To the best of our knowledge, this is the first study using a theory-based approach in facing these issues in adolescents with type 1 diabetes. In our sample, adolescents and caregivers showed high levels of self-care and contribution to self-care. We found that higher caregiver self-efficacy in contributing to patient self-care was associated with higher caregiver contribution to self-care.

Moreover, our results highlighted coherence between levels of self-care of adolescents and caregivers' contribution to self-care. This is relevant because it is the first contribution in describing the complex interplay between patients' self-care and caregivers' contribution to self-care in people with type 1 diabetes and could provide information on how this relationship works.

Caregiver self-efficacy in contributing to patient self-care was significantly higher in caregivers with a high contribution to self-care than in those with a low level of contribution to self-care maintenance, self-care monitoring and self-care management. This result is consistent with the middle range theory of self-care of chronic illness<sup>8,11</sup> and with previous studies in heart failure,<sup>33,34</sup> where the caregiver self-efficacy in contributing to patient self-care was found to be a strong determinant of caregiver contribution to self-care maintenance and management. This association also suggests the opportunity to enhance caregiver contribution through strengthening caregiver self-efficacy with customised interventions, education and information.<sup>34</sup>

We expected significantly higher contribution in female caregivers rather than males:<sup>35</sup> the absence of differences in our results could be due to the fact that the vast majority of caregivers were women, as is often the case.<sup>16</sup> In this way, the remaining small proportion of males was probably composed of particularly involved caregivers, who therefore did not differ significantly from women in terms of contribution to self-care. However, differences in caregiver contribution to self-care monitoring and management were found between caregivers whose patient had adequate and inadequate self-care. In particular, caregiver contribution was high when patients' self-care was adequate and vice-versa, which seems to reflect an aligned way of behaving within the dyad. Social support has been



**Figure 1.** Caregiver contribution (CC) to self-care according to the patient score of self-care maintenance, self-care monitoring and self-care management (SCODI).

associated with self-care,<sup>36</sup> so it is possible that, in our findings, where we found higher caregivers' contribution, we could have seen higher patients' self-care because of the support received. Otherwise, lower self-care and contribution to self-care might reflect a shared lower importance attributed to self-care in both caregivers and patients. Previous studies verified the same association in other chronic conditions.<sup>10</sup> Instead, the lack of significant differences in caregiver contribution to self-care maintenance between caregivers whose patient had adequate and inadequate self-care can be attributed to the wide variety of behaviours that this scale intends to investigate, for example, diet, hygiene, visits and medications.<sup>11</sup> In our sample, most of the caregivers were parents, and they may be very involved in these self-care maintenance behaviours, regardless of the adolescent's degree of self-care, coherently with previous studies.<sup>21,37</sup> In a previous study conducted in the Italian population,<sup>37</sup> adolescents reported that they perceived their parents as support and as facilitators to self-care. This may be linked to the positive role of parents' support in the Italian culture even in adolescence and young adulthood, in contrast with other contexts.<sup>37</sup>

The most frequently reported areas of caregivers' contribution, concerning diet, decision on boluses and control, reflected the daily involvement of caregivers in both core behaviours and a supervisory role.<sup>4,17</sup> This result suggests that providing caregivers with educational interventions could improve the glycaemic control of adolescents.

The lower frequency of contribution in the correction of hypo- and hyperglycaemia and night assistance could indicate the need to further investigate these aspects in future research. In fact, such an infrequent contribution could occur either because of clinical stability and autonomy of adolescents or lack of education of caregivers on these issues. If the latter was the case, specific educational interventions could be developed to support caregivers.

#### **Strengths and limitations**

The first limitation of the study is that data were collected in a single centre, so generalisation of results should be made with caution. Furthermore, as it was a pilot observation, the sample is quite limited, and some important variables of patients and caregivers might not have been included or analysed in this study, such as type 1 diabetes knowledge, adolescents' age groups, stress, anxiety and depression. Furthermore, we found that most participants had adequate self-care: it would be interesting in the future to explore more participants with lower self-care scores, to understand their characteristics and to identify specific areas of intervention. However, our setting was the regional referral centre for the research and treatment of diabetes in the developmental age: attracting patients from a region of 10 million inhabitants, it could be reasonable to consider the sample adequately heterogeneous. Another limitation is the cross-sectional nature of the study: the continuous evolution of adolescents would have deserved to be followed and studied over time.

Table 3. Caregiver characteristics according to caregiver contribution (CC) to self-care maintenance, self-care monitoring and self-care management.

N	CC to self-care maintenance		P-value	CC to self-care monitoring		P-value	CC to self-care management		P-value
	<70	≥70		<70	≥70		<70	≥70	
	43	110		73	80		90	63	
<b>Age (years)</b>	<b>Median [1st-3rd quartile]</b>			<b>Median [1st-3rd quartile]</b>			<b>Median [1st-3rd quartile]</b>		
	46 [43-51]	47 [43-50]	0.938	48 [44-52]	46 [42-49]	0.060	47 [44-51]	46 [42-49]	0.218
	<b>N (%)</b>			<b>N (%)</b>			<b>N (%)</b>		
<b>Gender</b>	13 (30)	29 (26)	0.779	23 (32)	19 (24)	0.372	25 (28)	17 (27)	1.000
	Male								
	30 (70)	81 (74)		50 (68)	61 (76)		65 (72)	46 (73)	
	Female								
<b>Nation</b>	32 (74)	82 (75)	1.000	48 (66)	66 (83)	0.029	64 (71)	50 (79)	0.335
	Italy								
	11 (26)	28 (25)		25 (34)	14 (17)		26 (29)	13 (21)	
	Other								
<b>Occupation</b>	5 (12)	12 (11)	0.091	9 (12)	8 (10)	0.675	11 (12)	6 (9)	0.379
	Unemployed								
	1 (2)	15 (14)		8 (11)	8 (10)		12 (13)	4 (6)	
	Housewife								
	36 (84)	82 (74)		55 (75)	63 (79)		66 (73)	52 (83)	
	Employed								
	0 (0)	1 (1)		0 (0)	1 (1)		0 (0)	1 (2)	
	Retired								
	1 (2)	0 (0)		1 (1)	0 (0)		1 (1)	0 (0)	
	Student								
<b>School education</b>	1 (2)	1 (1)	0.254	1 (1)	1 (1)	0.106	2 (2)	0 (0)	0.567
	Primary school								
	8 (19)	23 (21)		19 (26)	12 (15)		19 (21)	12 (19)	
	Secondary school								
	19 (44)	65 (59)		32 (44)	52 (65)		48 (53)	36 (57)	
	High school								
	15 (35)	21 (19)		21 (29)	15 (19)		21 (23)	15 (24)	
	University								
<b>Marital status</b>	2 (5)	2 (2)	0.058	2 (3)	2 (3)	0.269	2 (2)	2 (3)	0.283
	Single/Never married								
	33 (77)	97 (88)		61 (84)	69 (86)		77 (86)	53 (84)	
	Married/Cohabitant								
	8 (19)	10 (9)		9 (12)	9 (11)		10 (11)	8 (13)	
	Divorced/Separated								
	0 (0)	1 (1)		1 (1)	0 (0)		1 (1)	0 (0)	
	Widower/Widow								
<b>Relationship with the patient</b>	28 (65)	80 (73)	0.080	49 (67)	59 (74)	0.305	64 (71)	44 (70)	0.454
	Mother								
	13 (30)	29 (26)		22 (30)	20 (25)		23 (26)	19 (30)	
	Father								
	2 (5)	0 (0)		2 (3)	0 (0)		2 (2)	0 (0)	
	Brother/Sister								
	0 (0)	1 (1)		0 (0)	1 (1)		1 (1)	0 (0)	
	Grandparent								

Table 3. (Continued)

N	CC to self-care maintenance <70		CC to self-care maintenance ≥70		P-value	CC to self-care monitoring <70		CC to self-care monitoring ≥70		P-value	CC to self-care management <70		CC to self-care management ≥70		P-value
	N (%)		N (%)			N (%)		N (%)							
Control/supervision	18 (42)	46 (42)	35 (48)	29 (36)	1.000	36 (40)	28 (44)	0.702							
Night assistance	14 (33)	33 (30)	21 (29)	26 (32)	0.910	30 (33)	17 (27)	0.509							
Diet	24 (56)	65 (59)	39 (53)	50 (62)	0.852	49 (54)	40 (63)	0.342							
Decision on boluses	15 (35)	56 (51)	29 (40)	42 (52)	0.108	42 (47)	29 (46)	1.000							
Correction of hyper-/hypoglycaemia	12 (28)	40 (36)	26 (36)	26 (32)	0.422	38 (42)	14 (22)	0.017							
Set change	14 (33)	27 (25)	17 (23)	24 (30)	0.422	29 (32)	12 (19)	0.104							
Assistance in sport	2 (5)	13 (12)	4 (5)	11 (14)	0.299	4 (4)	11 (17)	0.017							
	<b>Median [1st-3rd quartile]</b>	<b>Median [1st-3rd quartile]</b>	<b>Median [1st-3rd quartile]</b>	<b>Median [1st-3rd quartile]</b>		<b>Median [1st-3rd quartile]</b>	<b>Median [1st-3rd quartile]</b>								
Number of caregiving activities	2 [1-3]	3 [2-3]	2 [1-3]	3 [2-3]	0.351	3 [1-3]	2 [2-3]	0.649							
Years of care	6 [2-8]	4 [2-8]	4 [2-8]	5 [3-8]	0.891	4 [2-8]	4 [2-8]	0.860							
Caregiver self-efficacy	77.27 [57.95-92.05]	86.36 [77.27-94.89]	77.27 [59.09-86.36]	89.77 [81.82-95.45]	0.022	77.27 [63.64-86.36]	90.91 [84.09-97.73]	<0.001							

\*More than one answer possible.



Nevertheless, the study design was coherent with the objectives of the study, aiming at obtaining an initial description of the phenomena of interest placed within the theoretical framework of the middle range theory of self-care of chronic illness.

## Conclusion

Findings suggest that caregivers can contribute significantly to the self-care of adolescents with type 1 diabetes. Using a theory-based instrument to measure caregivers' contribution to self-care could help identify those more at risk of ineffective contribution to self-care and develop tailored interventions. Furthermore, interventions aimed at empowering caregivers' self-efficacy could produce increments in their contribution to self-care.

Further research is required to deepen the understanding of the relationship between patient self-care and caregiver contribution to self-care. Specific attention should be given to how adolescents with type 1 diabetes perceive caregivers' contribution to self-care throughout adolescence and young adulthood, how they gain independence and how the dyad relationship affects this trajectory. The topic of the determinants of caregiver contribution to self-care in type 1 diabetes needs to be explored, as well as the effects on health outcomes. Lastly, the analysis of adolescence in smaller age groups, as well as longitudinal studies, could be used to understand how the relationship between patients' self-care and caregivers' contribution to self-care evolves over time, especially considering the progressive empowerment and autonomisation of adolescents with type 1 diabetes, and identify areas of intervention.

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