

Who are the beneficiaries and what are the reasons for non-utilization of respite care? A cross-sectional study on family caregivers

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Abstract

Background

Family caregivers assume substantial caregiving responsibilities for persons with chronic conditions, which leads to negative impact on their lives. Respite care is provided as a temporary relief for them. The design of appropriate respite care programs requires the identification of beneficiary subgroups for different types of services. The objectives of the study were to quantify the uptake of respite care services by family caregivers of persons with spinal cord injury, and to identify the main beneficiaries of the respective offers and the reasons for non-use.

Methods

A cross-sectional survey of family caregivers of persons with spinal cord injury was conducted nationwide in Switzerland. The use of 11 different respite care services during the last 12 months was investigated, along with caregivers' reasons for not using any respite service. Classification trees were used to characterize the beneficiaries and reasons for not using respite services.

Results

One-third of family caregivers used at least one type of respite care service during the last 12 months. Utilization of respite care was found to be greater among those who employed professional home care (57% vs 24% among those without professional home care). There were marked cantonal differences in the utilization of respite care. The primary reason for not using respite services was "no demand" (80% among non-users of respite services), mainly among caregivers who were less emotionally affected by their caregiving tasks.

Conclusions

Utilization of respite care services primarily depends on living arrangements and place of residency and less on the functional status of the care recipient. Programs should thus be tailored to the cultural context of their potential users. This is best achieved through coordination with local health care professionals who can identify the needs, provide information, initiate referrals, and integrate the care into a larger support plan.

Background

Informal care can have positive effects on the well-being of persons with chronic conditions [1]. Family caregivers are mostly involved in providing nursing, emotional, and practical support [2, 3]. They assume substantial responsibilities, which can have negative impacts on their lives [4, 5]. Respite care is available to provide relief to family caregivers through short breaks, advice, or social connections [6]. Services vary depending on whether they are provided by local municipalities, non-profit organizations, or private providers [7]. Utilization of respite care has been found to be generally low in different countries despite

high levels of need [8, 9]. The design of appropriate respite care programs requires the identification of beneficiary subgroups for different types of services [9, 10]. Although variations in respite use have been found among caregivers in relation to their age, cultural orientation, finances, and need for respite [11–14], the commonly applied regression modeling is not sufficient for identifying such subgroups. In regression models, a linear relationship is assumed, only additive effects are detected for average members of a population, and there is a risk of overfitting when considering many predictors. The options for modeling non-linear relationships are limited, and the interaction between predictors is difficult to interpret [15]. To balance these limitations, the present study thus proposes the use of classification trees as a tool to perform a comprehensive exploration of respite care utilization, considering a wide spectrum of predictors.

This study aimed to quantify the uptake of different respite care services for family caregivers, the reasons for non-use, and the respective predictors. Spinal cord injury (SCI) in Switzerland was used as an example of a complex chronic condition requiring long-term care. Specifically, the study aimed to 1) identify the utilization of various respite services and the characteristics of their main beneficiaries among family caregivers and 2) investigate the reasons for the non-use of respite services and the respective predictors.

Methods

Data collection

A survey of family caregivers for persons with SCI was conducted in Switzerland. Persons with SCI were contacted from August 2016 to July 2017 and asked to forward a questionnaire to their primary family caregiver. Their contact information was acquired from the Swiss Spinal Cord Injury Cohort Study (SwiSCI) database [16]. The study inclusion criteria for persons with SCI followed those of SwiSCI, focusing on persons with a chronic SCI for more than 2 years, aged over 16 years, and residing in Switzerland. The exclusion criteria were persons with SCI resulting from congenital conditions, new injury in end-of-life care, or neurodegenerative disorders. Persons with SCI who reported not having a family caregiver were excluded. “Family caregiver” was defined as a partner, direct relative, or relative-in-law who cared for or assisted the person with SCI in daily living at home. The inclusion criteria for family caregivers were age over 18 years and ability to fill out the questionnaire in one of the survey languages (German, French, or Italian).

Questionnaire and variables

The family caregivers were asked if they used any of the 11 respite care services over the last 12 months. For those who indicated not having used any respite care service, the reasons were classified among eight categories with multiple answers possible. Additional questions covered their socio-demographic characteristics, living situation, employment, finances, caregiving situation, and characteristics of the person with SCI. The caregiver’s quality of life (QoL) was measured with a single item about overall

quality of life (WHOQOL-BREF) [17]. Twelve items of the COPE-index [18] were used to capture the participant's perception of the positive and negative aspects of caregiving.

Data analysis

Odds ratios for respite care use were calculated between groups of study participants. Need for respite services was expressed as caregiving burden, operationalized by the caregiver's QoL, the care recipient's wheelchair dependency, and the caregiver's time investment in care.

Predictors of respite care service utilization were identified using classification and regression trees (CART) [15]. Separate classification trees were built for each of the 11 types of respite care services and for the use of any respite care service as outcomes. Another set of classification trees was built for the eight reasons for the non-use of respite services as outcomes. In all classification trees, 133 potential predictors were included (Supplementary Table 1). The results are summarized in tables with the most predictive subgroups for the respective outcomes. Data were prepared with Stata 16 for Windows (College Station, TX, USA). Classification trees were built with the R package "rpart" [19].

Results

Sample characteristics

Among the 4502 invitations, 1259 persons with SCI did not live with a family caregiver. Those excluded also included 532 persons who were ineligible based on other criteria, 397 untraceable contacts, 110 participation refusals, and 1487 non-responses. A total of 717 questionnaires were returned (response rate 31%), and of those, 679 answered the question about respite care (95%). The primary family caregivers were mostly female (72%), and the average age was 57 years old (Table 1). They were mostly the spouse of the person with SCI (76%), and 84% lived in the same household as their care recipient. The median care duration was 9 years, with a median time investment of 12 hours per week. One-third of the participants reported having used insurance-covered professional home care, with a median use of 8 hours per week.

Table 1
 Characteristics of the family caregivers and the persons with spinal cord injury

Characteristics	Statistics N = 679
Characteristics of the family caregiver	
<i>Sex–n (%)</i>	
Male	188 (27.7)
Female	488 (71.9)
<i>Age in years–mean (std)</i>	
	57.3 (13.9)
<i>Language region–n (%)</i>	
German	498 (73.3)
French	146 (21.5)
Italian	28 (4.1)
<i>Relationship to the SCI person–n (%)</i>	
Spouse/life partner	517 (76.1)
Mother/father	89 (13.1)
Child	35 (5.2)
Sibling	19 (2.8)
Other relative	7 (1.0)
<i>Living in the same household with the person with SCI–n (%)</i>	
	572 (84.2)
<i>Perceived quality of life–n (%)</i>	
Very good	150 (22.1)
Good	372 (54.8)
Neither good nor bad	131 (19.3)
Bad	10 (1.5)
Very bad	3 (0.4)
Characteristics of caregiving situation	
<i>Used at least one kind of respite care during the last 12 months–n (%)</i>	

Abbreviations: SCI = spinal cord injury; std = standard deviation; Q₂₅ = lower quartile; Q₇₅ = upper quartile.

Characteristics	Statistics
	N = 679
Yes	239 (35.2)
No	440 (64.8)
<i>Duration since taking care in years–median (Q₂₅–Q₇₅)</i>	9 (4–19)
<i>Time investment in caregiving in hours per week–median (Q₂₅–Q₇₅)</i>	12 (5–30)
<i>Other informal caregivers involved–n (%)</i>	279 (41.1)
<i>Hired professional home care–n (%)</i>	230 (33.9)
<i>Hired hours of professional home care–median (Q₂₅–Q₇₅)</i>	8 (4–14)
Characteristics of the person with SCI	
<i>Sex–n (%)</i>	
Male	499 (73.5)
Female	176 (25.9)
<i>Age in years–mean (std)</i>	56.4 (16.2)
<i>Time since injury in years–median (Q₂₅–Q₇₅)</i>	14 (5–26)
<i>Type of SCI–n (%)</i>	
Paraplegic	417 (61.4)
Tetraplegic	216 (31.8)
Missing	46 (6.8)
<i>Wheelchair dependency– n (%)</i>	
Completely dependent on wheelchair	464 (68.3)
Able to stand	22 (3.2)
Partially able to walk	166 (24.4)
Abbreviations: SCI = spinal cord injury; std = standard deviation; Q ₂₅ = lower quartile; Q ₇₅ = upper quartile.	

The numbers of missing values are less than 5% if not specified otherwise.

Quality of life was measured with a single item about overall quality of life (WHOQOL-BREF)

Utilization of respite care services and predictors of utilization

Respite care use was found to be higher among participants who reported having a low QoL (OR 1.55, 95% CI 1.06 to 2.26), whose care recipient was wheelchair dependent (OR 1.72, 95% CI 1.18 to 2.49), and who reported a large time investment in providing care (OR 2.34, 95% CI 1.69 to 3.25) (Table 2). One-third reported having used at least one type of respite care service during the last 12 months (Table 3). The most commonly used respite service was a driving service for the care recipients (16%), followed by household support (14%). Support groups and training courses were used by the fewest participants (1% each).

Table 2
Correlation between need for respite and respite care use

Need for respite indicated by burden	Odds ratio
Caregiver's perceived quality of life	1.55 (1.06–2.26)*
Wheelchair dependency	1.72 (1.18–2.49)**
Time investment in care	2.34 (1.69–3.25)***
Odds ratios were calculated based on simple logistic regression. Respite care use: 0 = used none; 1 = used at least one kind of service.	
Caregiver's perceived quality of life (measured with overall quality of life in WHOQOL-BREF): 0 = high quality of life (very good, good); 1 = low quality of life (very bad, bad, neither good nor bad).	
Wheelchair dependency: 0 = not fully wheelchair dependent (able to stand, able to walk); 1 = fully wheelchair dependent.	
Time investment in care: 0 = low investment (< sample median 12 hrs/week); 1 = high investment (≥ sample median 12 hrs/week).	
*=p < 0.05, **=p < 0.01, ***=p < 0.001.	

Table 3 Predictors of utilization of respite services during the last 12 months

Respite Service		Typical users		Typical non-users	
N = 679					
n (%)	Predictors	N ¹	n (%) ²	Predictors	N ¹ n (%) ²
Has used at least one kind of respite care 239 (35.2%)	→ Received professional home care	230	132 (57%)*	→ Did not receive professional home care	449 107 (24%)*
	→ Lived in canton of ZH, BE, UR, SO, BL, SG, GR, AG, TG, TI, VD	168	108 (64%)	→ Care service was not considered an important information topic	428 92 (21%)
	→ Inactive in association/organization (participated "monthly" to "never")	150	102 (68%)	→ Highly satisfied with own health	259 37(14%)
Types of services					
Driving service 108 (15.9%)	→ Received over 1.5 hrs/week of professional home care	220	64 (29%)	→ Received less than 1.5 hrs/week of professional home care	459 44 (1%)
	→ Lived in canton of ZH, ZG, BS, BL, SG, TI, GE	76	33 (43%)		
	→ Person with SCI injured less than 7 years ago	25	17 (68%)		
Household support 96 (14.1%)	→ Received over 0.75 hrs/week of professional home care	214	59 (28%)	→ Received less 0.75 hrs/week of professional home care	465 37 (8%)
	→ Lived in canton of UR, ZG, TI	16	12 (75%)	→ Lived in other cantons than SO, BL and VD	397 23 (6%)
Relief offer for holidays/short term home care 49 (7.2%)	→ Received professional home care	230	36 (16%)	→ Did not receive professional home care	449 13 (3%)
	→ Lived in canton of ZH, BE, SH, SG, GR, TG	96	27 (28%)		
	→ Family caregiver assisted in washing face and hands	32	14 (44%)		
Emergency call 38 (5.6%)	→ Family caregivers aged 72 years old or older	107	16 (15%)	→ Family caregiver younger than 72 years	572 22 (4%)
	→ Lived in canton of SZ, TI, VD, GE	22	10 (45%)	→ Highly satisfied with personal relationships	282 2 (1%)
	→ Family caregiver assisted in mobility in moderate distance	10	8 (80%)		
Advice 30 (4.4%)	No predictor identified	-	-	No predictor identified	- -
Respite assistance at home during the day 29 (4.3%)	→ Care service was considered an important information topic	88	15 (17%)	→ Care service was not considered an important information topic	591 14 (2%)
	→ Lived in canton of ZH, SG, GR, AG, GE	26	9 (35%)		
	→ Received financial compensation for caregiving	17	9 (53%)		
Day care in nursing home 27 (4.0%)	→ Family caregiver aged 67 years or older	197	19 (10%)	→ Family caregiver younger than 67 years old	482 8 (2%)
	→ Family caregiver lived in canton of SG, GR, NE	11	6 (55%)		
Night care 16 (2.4%)	No predictor identified	-	-	No predictor identified	- -
Social companionship/visit 16 (2.4%)	→ Family caregiver missed someone to talk to	129	10 (8%)	→ Family caregiver did not miss someone to talk to	550 6 (1%)
	→ Family caregiver lived in canton of SO, TI, VD, JU	23	6 (26%)		
	→ Family caregiver did not assist in washing feet	11	6 (55%)		
Support groups for family members 7 (1.0%)	No predictor identified	-	-	No predictor identified	- -
Training courses 6 (0.9%)	No predictor identified	-	-	No predictor identified	- -

* The predictor significantly predicted the outcome.

¹ N = the total number of participants in the respective nodes.

² n = the number of participants who utilized a particular service among the participants in the respective nodes; % = the percentage of participants utilizing a particular service in the respective nodes.

Abbreviations: SCI = spinal cord injury; CHF = Swiss Francs; Cantons were presented in abbreviations.

Utilization of respite care services was found to be higher among participants with professional home care (57% vs 24% among those without professional home care). Among those, up to 64% of the use was explained by the canton (region of residence). An association with professional home care was also found for specific types of respite care services: driving services (29% vs 1% among those with less than 1.5 weekly hours of professional home care), household support (28% vs 8% among those with less than

0.75 weekly hours of professional home care), and relief offers for holidays (16% vs 3% among those without professional home care). Utilization of professional home care and canton of residence were the strongest determinants of respite care utilization (Supplementary Table 2), and they were the primary predictors of the utilization of five types of respite care services and of the overall utilization of respite care. Receiving financial compensation was the most decisive factor for using daytime respite services, while assisting in feet washing was the most decisive for social companionship. Family caregivers' time investment in care was a weak predictor of respite care utilization, as was the care recipient's functional status, caregiver's satisfaction about their financial situation, and income.

<<< Table 3 >>>

Reasons for not utilizing respite care services and predictors

The most common reason for not using respite care services was “no demand”, specified by 80% of the 432 non-users (Table 3). Other reasons were “sufficient support by family or friends” (22%) and “uncomfortableness with strangers/family preference” (12%). Minor reasons included costs (9%), availability (3%), scheduling (2%), bad experience (1%), and mistrust (1%).

The reason of “no demand” for respite services was primarily linked to a less negative impact of caregiving on the caregiver's emotional well-being and to higher satisfaction with their financial situation. The vast majority (91%) of the participants with these characteristics reported not having a need for respite care, and this group constitutes 61% of the total non-user group. Participants who were negatively affected by caregiving and did not mention “no demand” for respite care were geographically clustered. Half of them lived in eight—mainly French-speaking—cantons (out of 26) and mentioned barriers other than “no demand”. Family caregivers who invested an excessive amount in care reported more often the care recipient's preference for family care as a reason for not using respite care services. The canton of residence was the most important factor for delineating the various reasons for not using respite care services (Supplementary Table 3).

Table 4 Predictors of reasons for non-utilization of respite services during the last 12 months

Reason for non-utilization N = 432 n (%)	Reason mentioned by		Reason not mentioned by			
	Predictors	N ¹	n (%) ²	Predictors	N ¹	n (%) ²
No demand 344 (79.6%)	→ Sometimes/never perceived caregiving as negative to their emotional well-being	402	336 (84%)*	→ Mostly/always perceived caregiving as negative to their emotional wellbeing	30	8 (27%)*
	→ Highly satisfied with their financial situation	264	240 (91%)	→ Lived in canton of FR, SG, AG, TI, VD, VS, NE, GE	15	0 (0%)
	→ Never perceived caregiving as negative to their relationships with friends	205	194 (95%)			
Sufficient support by family or friends 94 (21.8%)	→ Other informal caregiver involved	180	62 (34%)	→ No other informal caregiver involved	252	32 (13%)
	→ Lived in canton of ZH, BE, LU, SZ, NW, GL, ZG, FR, BL, SG, GR, AG, TI, VD, VS, NE	160	62 (39%)	→ Lived in other cantons than SH, GR, TI, VS, NE	216	20 (9%)
	→ Lower personal income (less than 6000 CHF per month)	64	35 (55%)	→ Care recipient aged younger than 74 years	188	13 (7%)
Care recipient uncomfortable with strangers/preference of family 53 (12.3%)	→ Family caregiver spent 30 hrs/week or more in caregiving	91	28 (31%)	→ Family caregiver spent less than 30 hrs/week in caregiving	341	25 (7%)
	→ Lived in canton of LU, SZ, OW, GL, FR, GR, AG, TI, VS, GE	36	20 (56%)	→ Sometimes/never perceived caregiving as negative to their emotional well-being	268	13 (5%)
	→ Family caregiver aged 54 years or older	29	20 (69%)	→ Did not assist in dressing lower body	231	6 (3%)
Too expensive/not covered by insurance 38 (8.8%)	→ Low quality of life ("very bad" to "neither good nor bad")	79	20 (25%)	→ High quality of life ("good" to "very good")	353	18 (5%)
	→ Live in canton of LU, SH, SG, AG, GE	18	11 (61%)			
Not available 13 (3.0%)	No predictor identified	-	-	No predictor identified	-	-
Inconvenient schedule 9 (2.1%)	→ Family caregiver spent 65 hrs/week or more in caregiving	21	3 (14%)	→ Family caregiver spent less than 65 hrs/week in caregiving	411	6 (1%)
	→ Lived in canton of GL, FR, BL	5	3 (60%)	→ Family caregiver did not live alone	383	3 (1%)
Bad experience with service provider 6 (1.4%)	No predictor identified	-	-	No predictor identified	-	-
No trust in service providers 3 (0.7%)	No predictor identified	-	-	No predictor identified	-	-

* The predictor significantly predicted the outcome.

¹ N = the total number of participants in the respective nodes.

² n = the number of participants who utilized a particular service among the participants in the respective nodes; % = the percentage of utilizing a particular service in the respective nodes.

Abbreviations: SCI = spinal cord injury; Cantons were presented in abbreviations.

Discussion

Regional variability was most decisive factor for respite care use and for the reasons for non-utilization. This finding agrees with that from a national study that found geographic variations in respite uptake among families with a member with an intellectual disability, as respite care is provided locally [20]. Similarly, health care use in Switzerland is linked to the cantonal supply of services and financing [21]. Households with persons with SCI tend to cluster in cantons where the SCI-specific services are well established [22]. However, the participants in the present study rarely mentioned unavailability as a reason for non-use. Although financial support varies across cantons [6], this did not seem to be a main driver, as only a few participants mentioned cost as a barrier to access respite care services, contrary to a previous study conducted in Australia [12]. Cultural characteristics, as described by the language region, did not fully explain the unequal local utilization of respite care services, although health care use varies across the different language regions in Switzerland [23]. As there are no national regulations for respite care, other local characteristics may be more influential, such as the passive views, family values toward respite care, and cantonal demographic features [9, 14, 21].

Family caregivers who employed professional home care were more likely to use respite care services. The two do not seem to be linked through the families' financial capacity, as it was found to not have an impact. The predictive power of caregiver burden on respite care utilization was small, though other studies have identified this as a strong determinant [24, 25]. As the use of home nursing has been associated with a higher physical dependency [26], these family caregivers seemed to need both sources of support. The results from the present study also confirm the previous finding that professional home care is the main source of temporary breaks and condition-specific consultations for the family caregivers [6].

It was not surprising that "no demand" was the most common reason for non-utilization. The statement of "no demand" was linked to the subjective perception of burden. Similar to the findings regarding the care of persons with dementia, the care for the person was the main consideration when deciding about utilization, and family caregivers rarely declared their needs for a break [8, 9]. Family caregivers may experience feelings of guilt or fear when leaving the care recipients alone [11, 26], or they may wish to maintain a positive aspect, such as close relationship with the care recipient [27]. Even when most family caregivers wish to continue the care by themselves, they trust health professionals as a reliable information source and acknowledge their central role in encouraging caregivers to use external support [27]. Because they are in close contact with the families, health professionals can identify the needs, if not explicitly expressed by the family caregivers, and provide information or initiate referrals [13]. As the perceived QoL of family caregivers might indicate the need for support, it is recommended that this indicator be included in clinical or routine assessments so services can be initiated for those who are in need.

Conclusion

Family caregivers provide high-intensity care over many years and prioritize the needs of the care recipients. Here, classification trees were used to identify that respite care use was primarily determined by contextual factors. The respite programs should thus be adapted to the cultural, regional, and personal contexts of their intended users. This is best achieved in coordination with local health care professionals who can identify the needs, provide individual information, initiate referrals, and integrate care activities into a larger support plan.

Abbreviations

CART

Classification and Regression Tree

COPE-index

Carers of Older People in Europe Index

QoL

Quality of Life

SCI

Spinal Cord Injury

SwiSCI

Swiss Spinal Cord Injury Cohort Study

WHOQOL-BREF

World Health Organization Quality of Life Brief Version

Declarations

Ethics approval and consent to participate

An application for ethics approval was submitted to the Ethics Committee of Northwest and Central Switzerland and registered as EKNZ No. 2016-00863. As no clinical parameter or health-related data were measured, the committee claimed no jurisdiction over this study. All participants signed and returned their informed consents along with the questionnaire, confirming that they understood the purpose of the study and their participation.

Consent for publication

Not applicable

Availability of data and materials

The datasets used and/or analyzed during the current study are available from the corresponding author on reasonable request.

Competing interests

All authors are salaried employees of organizations that are subsidized by the Swiss Paraplegic Foundation.

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collection, management, and interpretation of the data; or preparation, review, or approval of the manuscript.

Authors' contributions

JH and AG initiated the research question and conducted the data analysis. JH wrote the manuscript under the supervision of AG. NM and AS contributed to the interpretation of the results and the review and revision of subsequent drafts. All authors have reviewed and approved the manuscript.

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List Of Supplementary Documents

1. File name: Additional file_1

File format: .docx

Title: Supplementary file 1

Description: The file contains three supplementary tables. The first one lists all the predictors included in the data analyses. The second and the third list the most important predictors for each outcome.

2. File name: Additional file_2

File format: .pptx

Title: Results of classification trees presented in tree graphs

Description: The file contains the graphs of each classification tree, for which at least one predictor could be identified.

3. File name: Questionnaire_translated_EN

File format: .docx

Title: Questionnaire (English translation)

Description: The file contains the questionnaire, from which data of the present study were retrieved. It refers to an English translation of the original questionnaire.

Supplementary Files

This is a list of supplementary files associated with this preprint. Click to download.

- [5Additionalfile1.docx](#)
- [6Additionalfile2.pptx](#)
- [7QuestionnairetranslatedEN.docx](#)