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Spirituality and Caregiver Burden of People with Intellectual Disabilities: an Empirical Study

Fabiana Torres Xavier[1] · **Mary Rute Gomes Esperandio**[1]

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Abstract

In recent years, interest in topics related to disabilities has grown. However, little attention has been devoted to people who constantly care for family members with an intellectual disability (ID). Thus, this study evaluated the relationship between the caregiver burden of people with intellectual disabilities and spirituality. The applied method was quantitative, exploratory, descriptive, and cross-sectional. The instruments used to collect data were a sociodemographic questionnaire, including questions extracted from the WHOQOL-100 (spiritual domain), and the following scales: Centrality of Religiosity; Brief Spiritual Religious Coping; Religious and Spiritual Struggles; Zarit Burden Interview and Satisfaction with Life Scale. One hundred twenty-nine people participated in the study. The sample was categorized as "highly religious" (57.3%), and 61.24% had an overload classified between moderate (36.43%) and severe (24.81%). The use of positive spiritual/religious coping methods was considered medium ($M = 3.44$), and religious and spiritual struggles were low ($M = 1.71$). Results show that those who considered themselves "spiritual and religious" highly use positive spiritual religious coping and score light burden and more life satisfaction. Such results indicate the importance of being attentive to the role of this dimension when planning emotional, psychological, and existential/spiritual support assistance. Public policies should consider the spiritual and religious dimension of those exclusively caring for people with intellectual disabilities. Studies focusing on how spiritual care can be provided to this population should be intensified.

Keywords Intellectual disability · Spiritual/religious coping · Religious and spiritual struggles · Care overload · Spiritual care

✉ Fabiana Torres Xavier
fabi_tx@outlook.com

Mary Rute Gomes Esperandio
mary.esperandio@pucpr.br

[1] Pontifícia Universidade Católica do Paraná - PUCPR, Curitiba, Brazil

Introduction

The Brazilian Institute of Geography and Statistics (IBGE 2010) points out that in 2010 there were 2,611,536 people with some form of intellectual disability. However, statistical data on this group is not precise due to the conceptualization of diverse types of disability (Botelho and Porciúncula 2018) and differences in interpersonal relationships, public policies, biomedical models, and specialized literature.

The concept of intellectual disability (ID) used in the scientific literature in Brazil follows the global trend that states that disability can be identified "by significant limitations in both intellectual functioning and adaptive behavior," which encompasses many social and practical skills of everyday life and are originated before age 22[1] (American Association on Intellectual and Developmental Disabilities 2020). Adaptive behavior refers to skills, such as communication, social, academic, and use of community resources, according to Decree n.5296 of December 2, 2004 (Brasil 2004).

The role of society and family in the lives of people with intellectual disabilities (PWID) is fundamental for their development, based on a set of norms and social and cultural values. Nevertheless, the responsibility and the main care fall upon the family, given that they are essential in these people's socialization; the relationships within this context directly influence the other social sub-relationships of PWID. However, the care routine can overload the person who is the primary caregiver (Pimenta et al. 2010; Barros et al. 2017), usually represented by the female figure (Chou and Kröger 2014; Barros et al. 2017). Such overload is characterized by personal discomfort, changes in daily routine, social and professional life, financial losses, and excessive tasks related to the individual to be cared for (Barros et al. 2017).

In a literature review, Xavier and Esperandio (2021) show that caregivers' attitudes, beliefs, and personal conceptions influence the life and care routine of people with ID. Among the main elements that can interfere in this care process, it is essential to consider health, quality of life, socioeconomic issues, spirituality and religious beliefs, and human and cultural interrelationships.

The study highlights using spiritual and religious strategies to cope with stress also called "spiritual/religious coping." This strategy was one of the most adopted coping methods by PWID caregivers (Xavier and Esperandio 2021). This finding shows that the spiritual and religious dimension is a resource people use in suffering situations.

Cultural, spiritual, and religious beliefs can positively influence the way of understanding and searching for meaning in this context of care (Ho and Keiley 2003; Blacher et al. 2007; Edwardraj et al. 2010; Durà-Vilà et al. 2010). Nonetheless, despite this, religious and spiritual struggles can arise, such as blaming God, the devil, or evil forces for their mistakes/sins, interpreting the problems, or worsening the clinical picture as divine punishment (Exline and Rose 2005; Stauner et al. 2016; Esperandio et al. 2022).

[1] Note: The upper limit of the definition of the developmental period in the 11th edition of the AAIDD Manual (2010) was age 18; in response to new research findings on brain development, the upper limit of the developmental period in the 12th edition (2021) was raised to age 22.

When referring to spirituality in this study, it should be understood as the "way individuals seek and express meaning and purpose and the way they experience their connectedness to the moment, to self, to others, to nature, and the significant or sacred." (Puchalski et al. 2014, p.643). In this sense, spirituality differs from religiosity, although these terms may overlap several times. Religiosity involves a personal experience lived through beliefs, practices, and values linked to an established religion. As Esperandio (2014, p.808) observes, religion is "a social phenomenon defined by particular limits, expressed in a body of doctrines assumed by the faith community that shares the same beliefs."

Given the scarcity of studies on the role of spirituality and religiosity in the life of caregivers of a family member with ID (Xavier and Esperandio 2021), this work aims to investigate the relationship between spirituality and the caregiver burden of people with intellectual disabilities.

Method

The applied method was quantitative, cross-sectional, descriptive, and exploratory. According to Marconi and Lakatos (2003, p.187), this method makes it possible to delineate and analyze a specific population's facts, phenomena, and characteristics, with systematic data collection also being an analytical and rational method that contributes to a better understanding. Data was collected online through a questionnaire composed of sociodemographic data (such as socioeconomic level, academic level, religious affiliation, and religious beliefs; questions extracted from the WHOQOL-100, related to the spiritual dimension), and the following instruments: Centrality of Religiosity Scale—CRS; brief Spiritual Religious Coping Scale—SRCOPE-14; Religious and Spiritual Struggles Scale—RSSS; Zarit Burden Interview (ZBI); Satisfaction with Life Scale—SWLS). Data was hosted on the Qualtrics Platform (https://pucpr.co1.qualtrics.com/jfe/form/SV_0eVDOPBBZuFTkMJ).

The research was approved by the Research Ethics Committee—Process No. 4,390,450. Data collection took place between November 2020 and July 2021. Due to COVID-19[2] pandemic, recruitment and data collection took place exclusively on online social networks dedicated to the population of people with intellectual disabilities through the distribution of the survey link on these networks. Initially, 215 people participated in the study. Of these, 86 samples were excluded (76 for not completing all the questions and eight for being caregivers of people with autism and schizophrenia, without intellectual disability). Thus, 129 samples were included in the final study.

[2] COVID-19 —A disease caused by the SARS-CoV-2 coronavirus that causes respiratory syndromes, which emerged in late 2019 in China. In March 2020, the World Health Organization (WHO 2022) characterized the outbreak of the disease as a pandemic. In other words, cases of COVID-19 have quickly spread to various countries and regions of the world and, in many cases, caused death. Up to this date, February 14, 2022, approximately 5,800,000 deaths from the virus have been reported to the WHO (Source: https://covid19.who.int/).

The inclusion criteria were voluntary participation, being older than 18, understanding the issues, being a caregiver of a person with intellectual disabilities, and accepting the informed consent form—ICF. Caregivers of individuals with any disability other than an intellectual, mental, or neurodevelopmental disorder were not included. As for the analysis procedures, the data was analyzed using the Statistical Package for the Social Sciences—SPSS.

The Centrality of Religiosity Scale—CRS, created by Huber (2003) and validated in Brazil by Esperandio et al. (2019), assesses whether spirituality and religiosity are central in the lives of the people participating in the study. This scale assesses five components that express religion's centrality in life: public practice, private practice, ideological, intellectual, and religious experience. These components are the ground on which religious constructs are formed and activated. The sum of the indexes allows the categorization of the personal religious construct-system of individuals and groups into three levels: (1) highly religious (the religious system occupies a central position, i.e., religious content and beliefs exert a strong influence on the psychological system); (2) religious (the personal religious system merely holds a subordinate position within the personality's cognitive and emotional architecture; (3) non-religious: according to Huber (2009, p.21).

The Spiritual/Religious Coping Scale—SRCOPE-14 (Esperandio et al. 2018) aims to assess the spiritual and religious coping strategies employed in situations of stress and suffering. Seven items assess positive spiritual/religious coping, and another seven assess negative spiritual/religious coping. Positive spiritual/religious coping strategies "reflect a secure relationship with a transcendent force, a sense of spiritual connectedness with others, and a benevolent worldview. Negative religious coping methods reflect spiritual tensions and struggle within oneself, others, and the divine" (Pargament et al. 2011, p.51). Therefore, the answers to the 14 items, on a Likert scale from 1 to 5, allow the following classification, based on the scale parameters: none or negligible: 1.00 to 1.50; low: 1.51 to 2.50; average: 2.51 to 3.50; high: 3.51 to 4.50; very high: 4.51 to 5.00.

The Religious and Spiritual Struggles (RSS) scale was assessed using the full Brazilian version of the RSS scale-24 items (Esperandio et al. 2022). The RSS scale aims to measure six domains of struggles (Exline and Rose 2005; Exline et al. 2014): divine (negative emotions based on beliefs about God or the perceived relationship with God); demonic (concerns related to the belief that the devil or evil spirits are attacking and causing adverse events); interpersonal (concern about negative experiences with people or religious institutions); moral (struggles in an attempt to follow the own moral principles; worry or guilt related to committed offenses); doubt (discomfort generated by doubts or questions related to the own spiritual and religious beliefs); ultimate meaning (conflicts related to issues around meaning and purpose in life). The answers to the 24 items, on a Likert scale from 1 to 5, allow the following classification, based on the scale parameters: none or negligible: 1.00 to 1.50; low: 1.51 to 2.50; average: 2.51 to 3.50; high: 3.51 to 4.50; very high: 4.51 to 5.00.

The Zarit Burden Interview—ZBI-7 items, is an instrument used to assess the care burden of caregivers. This seven-item scale was validated by Gort et al. (2005) in the context of Palliative Care with the Spanish population and by Kühnel et al. (2020) in palliative care with the German population. In Brazil, the ZBI-7 items reached the reliability standard of the version adopted by the Ministry of Health (Brasil 2013). The

scale identifies the burden levels: light overload: up to 14 points; moderate overload: 15–21 points; severe overload: above 22 points (Brasil 2013, p.192).

The Satisfaction with Life scale (SWLS) (Diener et al. 1985) comprises five items that assess the global self-perception of satisfaction with life. As Pavot and Diener (1993) inform, "the Satisfaction with Life Scale was developed to assess satisfaction with the respondent's life. The scale does not assess satisfaction with life domains such as health or finances but allows subjects to integrate and weight these domains in whatever way they choose." The concept of satisfaction with life is defined as a cognitive and emotional assessment of the own life. This can occur globally or in specific aspects, such as family, work, school, and health (Diener et al. 1985). The five items are measured by a Likert scale that ranges from 1 ("strongly disagree") to 7 ("strongly agree). The scale presents seven categories that range from "extremely dissatisfied" to extremely satisfied. (Diener et al. 1985).

As Zwingmann et al. (2011, p. 352) pointed out, "before choosing a questionnaire for use in a specific study, it should thoroughly be reflected which religious/spiritual component or components should be addressed and which instruments ensure conceptually clear-cut operationalization." Thus, to ensure that the instruments to collect data on spirituality and religiosity would make sense both for religious people and for those who self-identify as spiritual but not religious, we also applied, with the validated scales, four questions extracted from the WHOQOL-100, to assess the spiritual domain: (1) Do your personal beliefs give meaning to your life?; (2) To what extent do you feel your life to be meaningful?; (3) To what extent do your personal beliefs give you the strength to face difficulties?; (4) To what extent do your personal beliefs help you understand problems in life? In addition, we also posed a question with multiple choices about how they considered themselves concerning their spiritual and religious experience: "I consider myself: a religious person; spiritual but not religious; a spiritual and religious person; or a person who does not believe in God" (Fleck et al. 1999).

The reliability of the scales was evaluated by Cronbach's alpha, presenting the following values: Satisfaction with Life–0.861; Zarit Burden Interview–0.896; SRCOPE-14–0.853; Centrality of Religiosity–0.802; RSS scale–0.917 (Maroco and Garcia-Marques 2006). Descriptive analysis of categorical and numerical variables was presented as frequencies (percentages) and means (standard deviation). The correlations between the scales were evaluated using the Pearson correlation coefficient, and the significance level was set at 0.05 (Filho and Silva Júnior 2009).

Results

Sample Characterization

(a) General Data

The survey contained 129 people, 91.5% women, 7.8% men, and 0.8% others (agender). The primary caregiver role was performed by 77.5% of mothers, 3.9%

by fathers, 2.3% by grandparents, 0.8% by siblings, 4.7% by paid professionals, and 10.9% by other caregivers.

As for the length of time these people have been providing care to PWID: 11.6% less than one year, 23.3% for 1 to 3 years, 14.7% for 4 to 6 years, 10.9% for 7 to 9 years, and 39.6% provide care for more than 10 years.

Regarding age, 7.8% were older than 60 years old, 14% were between 51 and 59 years old, 32.6% were between 41 and 50 years old, 45% were between 21 and 40 years old, and 0.8% were between 18 and 20 years old. As for marital status, 71.3% were married, or in a married situation, 14.7% were single, 13.2% were separated, and 0.8% were widows.

Regarding the educational level, 23.3% had a graduate degree, 29.5% were undergraduate, 10.9% had a not complete undergraduate degree, 19.4% finished high school, 4.7% had not completed school, 5.4% finished primary education, and 7% did not complete primary education. Regarding employment, 43.4% have paid work, 39.5% are unemployed, 10.1% are retired, and 7% are on leave receiving government benefits. Regarding financial issues, 27.1% said they had a monthly income of up to one minimum wage (in July 2022, one minimum wage was equivalent to US $ 221.95), 28.7% between one and three minimum wages, 10.9% between four and six minimum wages, 19.4% more than six minimum wages, and 14% preferred not to inform.

The sample consisted of participants from five regions of Brazil: Southeast–59%; South–28%; Midwest–7%; Northeast–4% and North–2%. The diagnosis percentages of the people receiving the care were 42.6% Down syndrome, 14.7% West syndrome, 14% Rett syndrome, 9.3% Fragile X syndrome, 7.8% Angelman syndrome, 3.9% multiple intellectual syndromes and comorbidities, 1.6% intellectual disability, 0.8% hypomelanosis of Ito, 0.8% Cri-du-Chat syndrome, 0.8% microcephaly, and 3.1% not yet defined. Regarding the degree of disability, the classification was as follows: 20.2% profound, 10.1% severe, 23.3% moderate, 17.8% mild, and 28.7% not yet specified. Regarding the age group of PWID: 42.6% were under 5 years of age, 16.3% were between 6 and 10 years, and 41.1% were over 11 years of age.

(b) The Spiritual and Religious Profile

Regarding religious affiliation, 26.36% were Catholic, 17.05% Spiritualist, 17.05% Evangelical (including Pentecostal, Neo-Pentecostal, and Protestant), and 2.33% Afro-Brazilian religions; 22.48% believe in God, but had no religious affiliation, 8.53% reported different religious affiliations. When asked if they consider themselves as a “religious” person, “spiritual but not religious,” “religious and spiritual,"; or something else, 26.4% responded that they see themselves as “religious”; 44.2% as “spiritual but not religious”; 24% “spiritual and religious”; and 5.4% “do not believe in God.”

The caregivers were asked about possible religious changes when they provided care to PWID: 78.3% answered that they did not change their religion, but 21.7% did. The reasons for the changes are diverse: 2.3% left because they did not feel welcomed due to the disability of their family member, 9.3% left voluntarily, and 10.1%

for other reasons (e.g., search for meaning and explanation, disbelief in leadership, search for new options, and disappointment when needed most).

The study sought to verify difficulties of a spiritual and religious nature in accepting the family member's disability, and 76.7% reported that they had no difficulty accepting the disability; 3.10% said they had difficulties, and 20.2% reported difficulties, but not for reasons related to spiritual and religious beliefs. When asked if they believed that the "disability" is a type of divine punishment for some mistake or sin committed, 82.2% reported they did not believe it, 13.2% were not sure, 0.8% answered they did believe so, and 3.9% had never thought about it.

As for spiritual and religious assistance, 65.1% said they had not received this type of care in the last 3 years, while 34.9% received it in diverse ways and from diverse sources. Spiritual assistance was provided through pastoral counseling, prayers, and passes. People linked to Christian churches, Spiritism, Johrei Fellowship, and the Beneficent Spiritist Center, *União do Vegetal* (Ayahuasca religion), offered this assistance.

The results of the statistical analysis of the Centrality of Religiosity Scale show that 57.5% are classified as "highly religious," 37.8% are "religious," and 4.7% are "non-religious." The descriptive statistical analysis showed that the dimension of S/R were expressed as follows: ideological ($M_{\text{Ideological}} = 4.53$; SD = 1.08), private practice ($M_{\text{Private\_Practice}} = 4.12$; SD = 1 0.23), religious experience ($M_{\text{Religious\_Experience}} = 3.96$; SD = 1.25), intellectual ($M_{\text{Intellectual}} = 3.77$; SD = 1.16), and public practice ($M_{\text{Public\_Practice}} = 2.88$; SD = 1.69).

Table 1 presents the frequencies of responses to the four items extracted from the WHOQOL-100 that assess the spiritual and existential dimension:

Spiritual/Religious Coping—SRCOPE-14

The SRCOPE-14 requests the participant to describe, in a few words, the most significant stress situation experienced in the last 3 years. The most stressful situations reported by them were lack of support in the care of PWID and care overload, issues related to health, discovery and acceptance of the diagnosis of the family member with ID, death of a loved one, COVID-19 pandemic, financial or professional issues, discrimination and social exclusion, change in lifestyle, marital problems, among others.

Positive spiritual/religious coping was classified as "medium" ($M = 3.44$; SD = 1.16), with a predominance of the collaborative style (in which the individual shares responsibilities with God), followed by a search for spiritual support (search for comfort and hope through God's love and care) and religious forgiveness (in which the help of religion is sought to change negative feelings) (Pargament 1997; Pargament et al. 1998; Panzini and Bandeira 2004). The use of negative spiritual/religious coping methods was low ($M = 1.62$; SD = 0.83) according to the parameters' scale.

Table 1 Results of spiritual and existential dimension

	Not at all (%)	A little (%)	A moderate amount (%)	Very much (%)	An extreme amount (%)
Do your personal beliefs give meaning to your life?	6.2	10.9	7	38.8	37.2
To what extent do you feel your life is meaningful?	3.1	9.3	8.5	41.1	38
To what extent do your personal beliefs give you the strength to face difficulties?	4.7	8.5	3.9	38	45
To what extent do your personal beliefs help you understand life's difficulties?	4.7	13.2	6.2	34.1	41.9

Data study analysis

Religious and Spiritual Struggles

Based on the scale parameters, the total RSS mean was considered low ($M = 1.71$; SD = 0.63). The results for each domain were: ultimate meaning ($M_{\text{Meaning}} = 1.89$; SD = 0.99); moral ($M_{\text{Moral}} = 1.87$; SD = 0.93); doubt ($M_{\text{Doubt}} = 1.80$; SD = 0.82); interpersonal ($M_{\text{Interpersonal}} = 1.79$; SD = 0.97); demonic ($M_{\text{Demonic}} = 1.52$; SD = 0.77); divine ($M_{\text{Divine}} = 1.41$; SD = 0.81).

The analysis demonstrated that two items (doubt—"Struggled to figure out what I really believe about religion/spirituality"—$M = 2.32$; SD = 1,43, and ultimate meaning—"Had concerns about whether there is any ultimate purpose to life or existence"—$M = 2.12$; SD = 1.31) had higher results when compared to all others. Conversely, two items had lower results (demonic—"Felt tormented by the devil or evil spirits"—$M = 1.35$; SD = 0.81; divine—"Felt angry at God"—$M = 1.27$; SD = 0.80).

Care Burden and Satisfaction with Life

The results indicate that 61.24% of the sample presented an overload between moderate (36.43%) and severe (24.81%). On the other hand, light overload was presented by 38.76% of the participants. Regarding the perception of satisfaction with life, the results show that the mean was 22.79 (SD = 6.80), which characterizes this sample as "slightly satisfied" with life.

Concerning each item on the SWLS, the frequency analysis shows that 48.83% agree and strongly agree and 29.45% slightly agree that "so far, they have achieved important things they want in life;" 34.88% agree and strongly agree, and 30.23% slightly agree that they are "satisfied with their life;" 27.13% agree and strongly agree and 34.88% slightly agree that "the conditions of their life are excellent;" 31.78% of the sample agree and strongly agree and 27.90% slightly agree that "in most ways, their life is close to their ideal;" 34.10% agree and strongly agree and 20.15% slightly agree that "if they could live their life over, they would change almost nothing."

Analysis of S/R Correlations, Care Burden, and Satisfaction with Life

The correlations involving the scales inherent to the dimension of spirituality and religiosity were analyzed below (Table 2).

Using Pearson's correlation coefficient, positive correlations between religious and spiritual variables were highlighted with ZBI Scale variables, except for the Religiosity Centrality Scale. The struggles with the highest correlations are divine (r 0.416; p 0.000) and ultimate meaning (r 0.330; p 0.000).

Regarding SWLS, negative SRCOPE presented a weak negative correlation ($r - 0.391$; p 0.000) and, when correlated with RSS, divine, and ultimate meaning domains showed a moderate negative correlation ($r - 0.452$; p 0.000 and $r - 0.502$; p

Table 2 Pearson correlation analysis of the S/R dimension

		Satisfaction	Centrality	Positive SRCOPE	Negative SRCOPE	Religious and spiritual struggles	Divine struggles	Meaning struggles	Inter-personal struggles	Doubt struggles	Demonic struggles	Moral struggles	Zarit (ZBI)
Satisfaction													
Centrality	*r*	**0.168**											
	p	**0.057**											
Positive SRCOPE	*r*	**0.028**	**0.736****										
	p	**0.749**	**0.000**										
Negative SRCOPE	*r*	**−0.391****	**.−0.095**	**0.065**									
	p	**0.000**	**0.286**	**0.463**									
Religious and spiritual struggles	*r*	**.−0.495****	**.−0.016**	**0.039**	**0.605****								
	p	**0.000**	**0.855**	**0.664**	**0.000**								
Divine struggles	*r*	**.−0.452****	**.−0.240****	**.−0.126**	**0.686****	**0.645****							
	p	**0.000**	**0.006**	**0.153**	**0.000**	**0.000**							
Meaning struggles	*r*	**.−0.502****	**.−0.082**	**.−0.059**	**0.500****	**0.826****	**0.561****						
	p	**0.000**	**0.356**	**0.508**	**0.000**	**0.000**	**0.000**						
Interper-sonal struggles	*r*	**.−0.262****	**.−0.093**	**.−0.067**	**0.336****	**0.652****	**0.231****	**0.338****					
	p	**0.003**	**0.292**	**0.448**	**0.000**	**0.000**	**0.009**	**0.000**					
Doubt struggles	*r*	**.−0.298****	**0.078**	**0.045**	**0.358****	**0.816****	**0.394****	**0.659****	**0.469****				
	p	**0.001**	**0.379**	**0.613**	**0.000**	**0.000**	**0.000**	**0.000**	**0.000**				
Demonic struggles	*r*	**.−0.322****	**0.213***	**0.268****	**0.423****	**0.681****	**0.298****	**0.472****	**0.377****	**0.392****			
	p	**0.000**	**0.016**	**0.002**	**0.000**	**0.000**	**0.001**	**0.000**	**0.000**	**0.000**			
Moral struggles	*r*	**.−0.375****	**0.009**	**0.056**	**0.368****	**0.832****	**0.417****	**0.649****	**0.505****	**0.783****	**0.447****		
	p	**0.000**	**0.919**	**0.525**	**0.000**	**0.000**	**0.000**	**0.000**	**0.000**	**0.000**	**0.000**		

Table 2 (continued)

		Satisfaction	Centrality	Positive SRCOPE	Negative SRCOPE	Religious and spiritual struggles	Divine struggles	Meaning struggles	Inter-personal struggles	Doubt struggles	Demonic struggles	Moral struggles	Zarit (ZBI)
Zarit (ZBI)	***r***	**. − 0.550****	**. − 0.023**	**0.110**	**0.452****	**0.386****	**0.416****	**0.330****	**0.249****	**0.303****	**0.122**	**0.292****	
	p	**0.000**	**0.792**	**0.214**	**0.000**	**0.000**	**0.000**	**0.000**	**0.004**	**0.000**	**0.168**	**0.001**	

* The *p* is significant at the 0.05 level; **the *p* is significant at the 0.01 level

Sources: Data study analysis

0.00, respectively). The correlation between ZBI and SWLS is negative ($r-0.550$; p 0.000). We also compare the applied scales and self-reported spirituality (Table 3).

Discussion

This study shows that carrying is a responsibility delegated mainly to women: mothers, grandmothers, and sisters, as corroborated in the literature (Edwardraj et al. 2010; Pimenta et al. 2010; Chou and Kröger 2014; Barros et al. 2017; Rodrigues et al. 2019; Ronca et al. 2019; Masulani-Mwale et al. 2019; Souza 2019).

The results indicate that caregivers' burden directly affects aspects related to self-care. This means an imbalance in care relationships, which can lead to a future risk of "*family claudication*" (Fernandes 2009; Ferreira 2011) or "*compassion fatigue*" (Day and Anderson 2011). Family claudication, which is applied in the care context, is an expression that defines "the inability of family members to offer an adequate response to the patient's multiple demands and needs" (Cárdenas 2009). Furthermore, the imbalance between the care provided to the other and the self-care can lead the person who cares to an emotional disconnection and apathetic attitude as a form of self-protection from empathic suffering (Klimecki and Singer 2011).

Bearing in mind that in many cases, those who provide daily care, predominantly women, neglect their own needs and self-care in favor of the dependent person (Tomaz et al. 2017), the overload related to this practice directly contributes to the worsening of the caregivers' health (Fernandes 2009; Bordini et al. 2018). Several factors can cause such behavior, such as lack of free time, difficulty and lack of confidence in dividing activities, and physical and mental fatigue (Barros et al. 2017).

In this study, a little more than half of the sample, 53.6%, did not have formal employment, which may indicate an "exclusive dedication" ("informal caregiver") to the care of the dependent family member and that the possible burden comes from this type of activity. According to the literature, exclusive dedication, the type and degree of the syndrome's impairment, and the prolonged care time may influence worse health outcomes and negatively impact the quality of life of these caregivers (Souza 2019; Tomaz et al. 2017).

Given the physical and emotional burden (Kühnel et al. 2020), these informal caregivers may find themselves vulnerable and develop some illness in a brief time (Nasser et al. 2018). As a way of alleviating this situation, Shahra Razavi (Guimarães and Hirata 2020, p.41) formulated the "Care Diamond," which argues that the provided care should not be just a female responsibility (as an unquestionable, culturally developed, and socially accepted practice), but should be provided by an interrelated network formed by the State, family, market, and community organizations, dynamically, socially and geographically contextualized to the environment in which it is inserted. Furthermore, the female caregiver's figure needs to be recognized by the family, society, and the State as someone who performs work/service essential to human development (Bordini et al. 2018).

Care activities are routine and strenuous activities that bring tiredness, abandonment, and other negative feelings, such as guilt, anger, and frustration (Bordini et al. 2018). Such difficulties, in the case of PWID, may be associated with

Table 3 Comparison between self-reported spirituality and scales

	Centrality of religiosity (average)	Satisfaction with life (average)	Care burden (average)	Positive spiritual religious coping (average)	Negative spiritual religious coping (average)
I consider myself					
A religious person ($N=34$)	4324 (highly religious)	23,059 (slightly satisfied)	16,971 (moderate burden)	4050 (high)	1706 (not at all)
Spiritual but not religious ($N=57$)	3628 (religious)	20,614 (neutral)	18,140 (moderate burden)	3208 (medium)	1669 (not at all)
A spiritual and religious person ($N=31$)	4303 (highly religious)	26,677 (satisfied)	14,065 (light burden)	3737 (high)	1429 (not at all)
I do not believe in God ($N=7$)	1.4 (non-religious)	22 (slightly satisfied)	14,286 (light burden)	1122 (not at all)	1714 (not at all)

Data study analysis

the need for improved health or even the desire to cure the syndrome and comorbidity. The reported suffering situations can contribute to a decrease in the perception of satisfaction with life. Therefore, the findings of this study point to the need to evaluate and value caregiver spirituality, given that this dimension is inherent to existential issues, to the search for meaning and purpose in life, in connection with e self, with the other, and with the transcendent—whether or not it is linked to a religious denomination (Esperandio 2020). Many people find meaning and purpose in their lives in other sources or options unrelated to religion, such as art, music, nature, and helping others (Koenig 2012; Esperandio 2020). The participants of this study distinguish spirituality and religiosity. Studies argue that people with higher levels of education have lower adherence to institutionalized religion, either due to subjective personal factors (Mezzomo et al. 2019) or due to cultural clashes between science and religious beliefs (Swatowiski et al. 2018; Maraldi and Dias 2019), and the sample of this study seems to show a similar fact.

This deinstitutionalization process is not necessarily a break from spiritual and religious beliefs and values. However, it can be a process of "de-identification" and not belonging to faith communities due to stigmas and negative views related to disabilities in these communities (Edwardraj et al. 2010; Chiu et al. 2012; Chou and Kröger 2014; Masulani-Mwale et al. 2018; Masulani-Mwale et al. 2019). In addition, the data demonstrates the self-perception of this group as being more spiritual than religious and the spiritual dimension as an essential source of coping strategies in situations of suffering, as evidenced by the results of the Spiritual/Religious Coping scale.

The results also indicate that the factors that most influenced the change of religion were relational issues, feelings of exclusion, and the search for a new meaning and purpose in life. Such results may corroborate the results of the RSS scale, which, although modest, indicate that moral, meaning, and doubt struggles are the most prevalent. Moreover, these struggles are related to the search for meaning and purpose in life.

The literature shows that RSS is associated with fragile physical health, depressive symptoms, emotional distress, and suicidal ideation (Exline et al. 2014). Furthermore, psychological and spiritual suffering arising from lack of trust, anguish, doubts, and lack of meaning can be predictors of family caregivers' more significant stress and illness (Masulani-Mwale et al. 2018). Regarding correlations, although it is not possible to establish a cause-effect relationship (Barbetta 2002), the findings suggest that RSS presents a positive correlation with care caregiver burden and with negative SRCOPE. This suggests that as the care burden rates increase, so do the rates of RSS, in the same direction and vice versa.

Having a child with an intellectual disability is generally a situation that demands a process of elaboration, for instance, mourning the idealized baby, dealing with guilt and shame for not having a "perfect child," and finding meaning in suffering. The domain of spirituality can help people cope with suffering (Pargament 1997).

Based on the concept of spirituality and religiosity assumed in this study, the comprehensive training of a spiritual caregiver for working with this population is suggested. It is recommended that such assistants have, preferably, training in theology

and some knowledge of psychology for application in care contexts, and they also should develop skills and competencies to care for people who have strong religious beliefs or whether they consider themselves just spiritual people. Viktor Frankl (1992, p.113) highlights the importance of dealing with the phenomenon of faith, not necessarily faith in God, but faith in a broader interpretation, faith in the purpose and meaning of life, and faith in principles and values. In Frankl's conception, the spiritual (noetic) dimension is more anthropological than religious (Aquino 2013, p.44).

The present sample, classified as "highly religious," is consistent with the characteristics of the Brazilian population (Huber and Huber 2012; Esperandio et al. 2019). By collecting data on how they define themselves with their own religious experience, it was found that those who declared themselves "spiritual and religious" also made high use of positive spiritual/religious coping and had the lowest level of burden (in relation to other groups) and demonstrate greater satisfaction with life. This fact can corroborate the literature on the contributions of spirituality and religiosity as promoting aspects of health improvement. Furthermore, although no data was collected on how religious assistance was performed, it was observed that religious beliefs function as a search for meaning and resource to deal with the difficulties experienced.

The public practice of religious experience was the least punctuated dimension. In contrast, ideological and private practices prevailed, suggesting that spirituality and religious beliefs gain prominence in the search for existential meaning and as a coping resource to the detriment of participation in faith communities. However, this dimension needs to be addressed in studies and care practices. Thus, public policies should consider the spiritual and religious dimension of those exclusively caring for people with intellectual disabilities. Studies focusing on how spiritual care can be provided to this population should be intensified.

Conclusion

This paper investigates the relationship between spirituality and the caregiver burden of people with intellectual disabilities. Spirituality and religious beliefs play a fundamental role in the lives of these caregivers, and correlation analyses indicate that this dimension can interfere with the perception of satisfaction with life and caregiver burden. While negative aspects related to spirituality and religiosity occur (use of negative SRCOPE and the presence of RSS), the perception of satisfaction with life tends to decrease. The data also indicates that the care burden increases with high RSS. Such results suggest the importance of further studies to assess the relationship amidst RSS, caregiver burden, coping styles, and the role of the spiritual assistant/caregiver in this healthcare context.

Given the influence of the spiritual/religious dimension in coping with suffering in the routine care of people with ID, as this study has demonstrated, it has been concluded that assessing and including the spiritual dimension in providing care for caregivers of people with ID is necessary. It is essential to offer empathic, compassionate, humanized spiritual care that considers the uniqueness of these people's spiritual and religious beliefs. Theology can contribute to understanding how S/R

works in this context of care and to the delivery of subsidies that support the creation of proposals that integrate S/R into the care of those who care.

Data points to the need to understand the experience linked to the sacred and transcendent, the role of personal beliefs, and S/R assistance and care in health care. In this scenario, the possibility of the action of theology stands out in training community leaders and spiritual assistants/caregivers, working with multidisciplinary healthcare teams, and discussing and elaborating public policies to care for this population. Finally, this study can contribute to the literature on spirituality and health and subsidize public or private research and initiatives focused on the care of caregivers of people with intellectual disabilities in Brazil or Latin America.

Limitations

The main limitations of this study are (1) the size of the sample and the distribution. The sample size did not allow for the exploration of correlation (only a comparison), pointing to the differences in the burden of care and spirituality of those four categories: "religious"; "spiritual but not religious"; spiritual and religious"; "non-believer." Most of the participants live in the South and Southeast of Brazil. It has some impact on financial income as well as education level. Such variables can influence the results of burden and perception of satisfaction with life; however, these questions were not verified given the snowball method of the research distribution. (2) The research did not have the scope to evaluate the spiritual dimension and its correlation with the formal (professional) caregivers' burden. Future studies should investigate the relationship between spirituality, the burden of care, and spiritual assistance for this population.

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Declarations

Conflict of Interest The authors declare no competing interests.

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