



Spirituality and the Quality of Life of Individuals with Intellectual Disability

RESEARCH

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ABSTRACT

Context: Spirituality seems to form part of person-centred care planning and needs assessment of persons with intellectual disability. Yet, the role of spirituality in relation to their quality of life (QoL) has scarcely been investigated.

Objective: This paper reports on an exploration of the extent to which spiritual beliefs and practices were linked to individuals' perceptions of quality of life in two types of care services: one a faith-based provider, the other a non-faith-based service.

Method: A mixed-methods approach utilising the Quality Of Life Questionnaire (QOLQ) and the brief spiritual beliefs inventory for use in quality of life research (Systems of Belief Inventory-15R) was used to interview people with intellectual disabilities (or, if they lacked capacity, their formal carers) who lived in their respective service for a long time.

Findings: Participants living in the faith-based care service recorded higher mean and median scores on the QOLQ compared to their colleagues who resided in the non-faith-based care service. Further analysis indicated significant correlations between the spirituality measure and most of the QOLQ domains.

Limitations: The study sample of 36 makes generalisations difficult, and our initial intention to include a range of faith traditions was unsuccessful.

Implications: Further academic studies exploring spiritual issues for people with intellectual disabilities are needed, as well as clearer policy and practice guidelines and a willingness on the part of services to support this aspect of life.

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INTRODUCTION

Quality of Life (QoL) is a complex construct (Alborz, 2017; Van Hecke et al., 2018) that has both subjective and objective interconnected components (Bertelli, 2020; Van Hecke et al., 2018). The subjective aspect of QoL focuses on satisfaction and evaluation of life experiences (Narvaez et al., 2008; Nieuwenhuijse et al., 2019); whereas, objective QoL features the level of participation in societal institutions (e.g., work and education) (Narvaez et al., 2008) as well as the physical and social environment (e.g., Schalock & Keith, 1993: p. 2; Nieuwenhuijse et al., 2019). Whilst Hensel and colleagues (2002:p. 97) argued that a comprehensive measure of QoL should include both subjective and objective measures, some conceptualisations of QoL focus on the subjective (including the person's perceptions of the 'objective' aspects of employment, education, etc.). For example, Schalock and colleagues (2002) elaborated on the subjective components to include 'perceptions of well-being, feelings of positive social involvement, and opportunities to achieve personal potential' – the latter being akin to self-actualisation in Maslow's hierarchy of needs.

Social care services work towards meliorating the QoL of individuals who are not capable of complete independent long-term care (Malley & Fernández, 2010), including individuals with intellectual disability (ID); social care services do not aim to treat impairments, rather they endeavour to provide both functional and domestic support. Such support may include intimate tasks, including administering medications, washing, and dressing (Malley & Fernández, 2010). Whilst the independent regulator of health and social care in England, the Care Quality Commission (CQC), lists 530 ID community services out of a total of 1,348 registered community services (CQC website accessed in May 2022) and 5,405 ID care homes out of a total of 15,001 registered with CQC, only 37 of the ID care homes are faith-based (16 Christian and 21 Jewish accommodations). We found no further data offering a comprehensive overview of faith-based providers of ID services.

Faith-based service providers generally refer to spiritual and religious values as the guiding principle of their organisation (Solari-Twadell & McDermott, 1999). These types of organisations tend to be registered charities that are also regulated by CQC. Whilst both faith and non-faith-based services will generally recruit staff from diverse backgrounds, faith-based services often recruit volunteers in addition to paid staff.

People with an ID often require additional support to carry out ordinary daily activities, such as getting up in the morning, dressing, cooking, and using public transport. Covid has highlighted the additional support needs of people with ID to use virtual technology,

including computers and mobile phones, reiterating the importance of support for individuals to fulfil all aspects of societal life as a significant goal of the disability community (Ault et al., 2021). Having religious and/or spiritual quests may well be one of these important aspects for some individuals with ID. Yet research (e.g., Sango and Forrester-Jones, 2017; Turner et al., 2004) practice (see Bertelli et al., 2020; Carter, Biggs & Boehm, 2016; Sango & Forrester-Jones, 2019), and policy (Sango & Forrester-Jones, 2014; Whiting & Gurbai, 2015) indicate that little attention has been paid to this aspect of people's lives; whilst the spiritual rights of children are recognised in the United Nations Convention on the Rights of the Child (UNCRC), they do not feature in the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) (see Whiting & Gurbai, 2015).

Although a consensus as to what defines spirituality has yet to be reached, we adopted a multidimensional approach (see Garssen, Visser & Pool, 2021; Hill et al., 2000; Sango & Forrester-Jones 2019: pp.150–151; 2017:pp. 281–282 for further elaboration) that, briefly stated here, takes as its base a 'belief in supernatural phenomena' that consists of transcendence or supernatural existence; connection and relationship (with self, others, nature, the supernatural, or a higher being); and meaning and purpose (making sense of life, striving for answers). These dimensions can be rooted in one of two aspects of spirituality, including religious spirituality (i.e., social practices and expression of belief such as church attendance, worship, prayer, etc.) or non-religious spirituality (i.e., belief in the supernatural without necessarily socially practicing, meditation, belongingness, etc) (detailed in Sango & Forrester-Jones 2019:pp. 150–151). Evidence in the fields of general health (Cherblanc et al., 2021; Chlan, Zebracki & Vogel, 2011; Coppola et al., 2021; Counted, Possamai & Meade, 2018; Dezutter et al., 2010a; Dezutter et al., 2010b; Thune-Boyle et al., 2006) and mental health (Bonelli & Koenig, 2013; Forrester-Jones et al., 2018; Garssen, Visser & Pool, 2021) point to the role and importance of religious and spiritual beliefs and practices in the lives of individuals (Panzini et al., 2017).

Similarly, the few studies that exist in relation to spirituality and people with ID (see Liu et al., 2014; Rambow, 2016 (unpublished thesis); Swinton, 2002) have found that a belief in God or a higher power and participation in religious rituals can provide a framework within which individuals can make sense of their life experiences as well as affording them with a sense of security, acceptance, and hope, and providing them with a significant source of comfort and a route to social support networks (see Bacon, 2021 (doctoral thesis); Biggs & Carter, 2016; Forrester-Jones et al., 2006; Sango & Forrester-Jones, 2019). Carter (2021, 2021a, 2021b) further emphasised how a sense of belonging, which is

rooted in relationships and characteristics of reciprocal relationships such as love and acceptance (Carter & Boehm, 2019; Carter, Biggs & Boehm, 2016), may be found through participation in shared spiritual practices and congregational activities, with Hunter and Kivisto (2019) finding strong allegiances to religious faith by young people with ID. A growing number of studies (e.g., Bassett et al., 1994; Forrester-Jones, 2014: pp. 165–174; MacGregor, 2021) have also found that people with ID can understand spiritual matters in connection with life events including death (Forrester-Jones, 2013; Forrester-Jones et al., 2022). A recent study by Haider and Zaman (2022) exploring the cognitive understanding and subjective feelings of bereavement in adolescents with ID found that participants understood and interpreted death in the context of religious teachings.

However, few studies have purposefully measured the relationship between spirituality and QoL of individuals with ID (Carter, 2021b). Poston and Turnbull (2004) qualitatively explored the quality of life of parents and siblings of children with a disability, finding that spirituality and participation in religious communities were meaningful to their lives. Büssing, Broghammer-Escher, Baumann, and Surzykiewicz's (2017) cross-sectional study found that the relational aspects of spirituality (in particular, feelings that 'God was on their side') correlated best with the life satisfaction of people with Down Syndrome. However, whilst Büssing and colleagues (2017) measured individuals' beliefs with only one item of QoL (i.e., 'subjective general life satisfaction'), our study adopts a scale that addresses both subjective and objective aspects of QoL in relation to spiritual/religious belief and practice.

Amongst the possible factors and variables identified by a realist review (Bigby & Beadle-Brown, 2018) to influence QoL of people with ID, spirituality or religion was not mentioned. Evidence was strongest for staff practices (use of Active Support), front-line management practice, service culture, human resources policies and practice, adequate resources, and small dispersed and homelike settings. The lack of evidence for spirituality and religion in Bigby and Beadle-Brown's (2018) review further illustrates how spirituality and religion are often neglected by research in relation to people with ID. This was recently confirmed in a systematic mapping of literature on the relationship between spirituality and QoL in people with ID and/or Low-Functioning Autism Spectrum Disorders (LF-ASD) between 1996 to 2015 by Bertelli and colleagues (2020). Bertelli and colleagues (2020) found that of the 121 articles identified to be potentially relevant, upon further review only 44 were useful in answering their review question regarding the relationship between spirituality and QoL in people with ID. Bertelli and colleagues (2020) argued that these 44 papers illustrated low-level evidence as most consisted of expert opinions and descriptive studies.

AIM AND RESEARCH QUESTION

In this paper we report the findings of a study examining the role of spirituality on the QoL perceptions of individuals with ID living in a faith-based (Adam's House (AH))¹ and a non-faith-based (Greenleaves (GL))² residential care service. The research questions were (1) do religious and spiritual beliefs and practices relate to the QoL perceptions of individuals with ID in two dissimilar residential settings, and (2) if so, in what way? The findings reported in this paper form part of a larger study that has been published elsewhere (i.e., Sango & Forrester-Jones, 2018; 2019). Though the methodologies and participants employed are the same, a majority of the findings and conclusions differ substantially, with the current paper illustrating findings on how spirituality relates to QoL perceptions of persons with ID.

METHODS

SAMPLE AND SETTING

Non-probability selective sampling was used whereby local authority-regulated long-term care homes, both located in South East England, were chosen because they fitted our criteria of two dissimilar services regarding statements of faith. AH operates on a Christian philosophy and includes nine supported living homes (3–6 residents lived in each house) with 24-hour care provided by live-out and live-in volunteer and paid carers. GL is a secular provider, consisting of three residential houses (3–11 residents in each house) and staffed via a 24-hour care system by paid carers who do not live in the homes. Whilst the two services are not identical in nature, the purpose of the study was to explore whether religious and spiritual beliefs in a supreme being and practices, as well as social support gained from religious and/or spiritual affiliation, contribute to the QoL perceptions of individuals with ID in two dissimilar residential settings in Southern England.³

MATERIALS AND PROCEDURE

The UK National Health Service Ethics Committee (Ref: 13/LO/0594 for further details) gave the study a favourable ethical opinion. Participation was voluntary, without inducement, and for the 17 participants who lacked capacity to consent, we utilised consultees and nominated consultees in line with section 34(a) and 34(b) of the 2005 *Mental Capacity Act*. Sandelowski (2000) argues that spirituality is a complex phenomenon that cannot be adequately explored using a single research method. Thus, we employed both quantitative and qualitative methods. Quantitative and qualitative data were collected simultaneously, analysed independently, and combined to gain a holistic understanding of participants' perspectives (Creswell et al., 2011).

Schallock and Keith's (1993) Quality of Life Questionnaire (QOLQ) and a brief spiritual beliefs inventory for use in quality of life research (Systems of Belief Inventory – SBI-15R by Holland et al., 1998) were utilised. Schallock and Keith's (1993) QOLQ was chosen above other QoL instruments for its appropriateness for the sample: taking on average 20–30 minutes to complete compared with Cummins's (1997) Interview Schedule that takes up to two hours to administer. The QOLQ is also regarded as nuanced and robust in that it contains four quality of life domains (with both objective and subjective measures of QoL interlinked): (1) satisfaction scale (i.e., satisfaction with general aspects of life, such as living arrangements, family, social settings, etc.); (2) competence/productivity scale (i.e., voluntary or paid employment: skills learnt, ability to do their job well, etc.); (3) empowerment/independence scale (i.e., decisions about aspects of their life, such as the activities they were involved in), and (4) social belonging/community integration scale (i.e., how involved they were within their communities, such as the amount of activities they participated in).

Administration of the QOLQ interview is entirely verbal and risked being overly difficult for participants to understand and, for those with communication difficulties, to respond to. This risk was minimised by utilising smiley faces depicting feelings of happiness, neutral, and sad to denote 'very well', 'not at all well', 'very satisfied' for 10 of the 40 closed questions. Some of the questions were also paraphrased to aid comprehension. Where individuals lacked capacity to consent, two members of staff who knew the individuals well completed the QOLQ separately without consulting one another; scores were then averaged for each QOLQ domain. Where participants used Makaton or another form of communication, key workers accompanied the researcher at the interviews and translated the responses.

Good inter-rater reliabilities for the QOLQ were calculated from staff-staff ratings of participants who lacked capacity and for those who were non-verbal. These ranged from 0.66 to 0.83, with an overall reliability coefficient of 0.83 (see Rapley, Lobleby & Bozatzis, 1994). Participant-staff correlations, (i.e., residents' own ratings correlated with staff ratings) ranged from 0.46 to 0.81 for individual domains and 0.73 for the total scale. These showed a high agreement between self-report and externally rated versions of the questionnaire (see Cummins 1997; the QOLQ Manual, Schallock & Keith, 1993: p. 19).

The SBI-15R 'measures religious and spiritual beliefs and practices, and the social support derived from a community sharing those beliefs' (Holland et al., 1998: p. 460) as a potentially mediating variable in coping with life conditions and QoL. An analysis of SBI-15R by Holland and colleagues (1998) reported high internal

consistency for data: Cronbach's alpha 0.92 for Subscale 1; Cronbach's alpha 0.89 for Subscale 2, and Cronbach's alpha 0.93 for all 15 items together (more details on the SBI-15R can be found in Holland et al., 1998; Sango & Forrester-Jones, 2018).

Both the QOLQ and SBI-15R were administered as part of face-to-face semi-structured interviews that commenced in the second month of a 12-month program of fieldwork (six months was spent in AH and another six months was spent in GL). This enabled the first author to integrate within the communities and to build rapport and trust with participants and staff. The interviews lasted between 15 to 40 minutes depending on the verbal capability of each participant and were recorded and later transcribed verbatim by the first author.

ANALYSIS

A non-parametric Man Whitney U test was applied to test for differences in QoL (QOLQ) and spirituality (SBI-15R) between AH and GL using SPSS-22, with a Spearman Rho correlation testing for any relationship between the SBI-15R and QOLQ data pertaining to any influence spirituality had on service participants' perceptions of their QoL. Tables 2 and 3 indicate the manually calculated effect sizes for significant and non-significant P values using $r = Z/\sqrt{N}$ (r = effect size; z = z value; N = Observation number (Rosenthal, 1994)). Utilising NVivo V10 (QSR International, 2012) to manage the data, and following Braun and Clarke's (2006) six-step thematic analysis, we familiarised ourselves with the transcribed data, reading through texts and making initial notes. Both authors then independently coded each line of text. Patterns among the codes were identified and used to generate theme and subthemes. These were reviewed by comparing them against the whole data set and ensuring that quotes pertaining to each theme and subthemes accurately embodied the data. A spider diagram aided this process and helped with defining and naming themes. A final discussion between both authors followed until themes were agreed upon.

RESULTS

SAMPLE CHARACTERISTICS

Of the 41 participants invited (19 living in GL; 22 in AH); 36 ($n = 18$ in AH; $n = 18$ in GL) agreed to participate in the study. Whilst all the participants had been diagnosed with ID, at some point in their lives, case files revealed that 44.4% (8 out of 18) of those residing in AH had a diagnosis of moderate ID and 38.9% (7 out of 18) of those in GL had mild ID (see Table 1). All participants were White British, mainly male ($n = 25$ males) and aged between 21 and 71. Around 40% had lived in their respective service for over 10 years.

	ADAM'S HOUSE	GREENLEAVES	OVERALL
Sample number	18	18	36
Gender			
Male	9	16	25
Female	9	2	11
Age			
Mean	48.72	45.28	47
Median	54.00	49.50	51.75
Range	21-71	23-67	21-71
ID condition			
Mild	2	7	9
Moderate	8	2	10
Severe	6	5	11
Profound	2	4	6

Table 1 Service users' ($n = 36$) demographic data.

Note: ($n = 36$) is the total number of participants.

PARTICIPANTS' REPORTED SPIRITUAL BELIEF (SYSTEM BELIEF INVENTORY-15R) SCORE

The total sample scores for the SBI-15R (Holland et al., 1998) presented in Table 2 shows that individuals from AH reported higher scores on the Beliefs in a Supreme Being and Practices subscale as well as Social Support gained from their religious and/or spiritual affiliation compared with their colleagues from GL. Participants in both AH's and GL's spiritual and religious practices were either rooted in the Christian or Catholic religion.

FINDINGS FROM THE QOLQ

The QOLQ was used to measure how participants felt about different areas of their lives. As displayed in Table 3, significant differences were indicated between the two groups in relation to Satisfaction, Competence, and Social belonging, but not for Empowerment.

QOLQ satisfaction domain and SBI-15R

A finding of significant difference for satisfaction scale (see Table 3) indicates that participants from AH reported being more satisfied with their life in general compared to those in GL. For example, individuals from AH reported deriving more enjoyment out of life, were satisfied with their living arrangement, were less likely to feel out of place in a social setting, were more likely to feel that their families made them feel like an important part of the family, and were less likely to feel lonely. Further analysis (see Table 4) revealed that the Satisfaction scale was not significantly correlated with SBI-15R's B&P or SBI-15R's SSC. These data seem to highlight that those individuals who had a spiritual belief and practiced their belief via religious rituals including prayer and church services in both care services reported more general life satisfaction.

For example, they were more likely to indicate that they gained 'lots' of 'fun and enjoyment out of life' and were 'less likely to feel lonely' in any given month.

QOLQ competency/productivity domain and SBI-15R

Significant differences in the competence/productivity scores (see Table 3) reveal that more service users from AH were in employment (voluntary and/or paid). These participants also reported that they derived satisfaction, enough money, and new knowledge and skills from their job compared to their GL counterparts. The competence/productivity scale was significantly and positively correlated with SBI-15R's B&P and SBI-15R's SSC as seen in Table 4. This seems to show that individuals who reported that they were more spiritual and received more social support from their spiritual community were also most likely to report positive perceptions about their jobs (i.e., that they were 'very good' at their job and received positive feedback from others at work and that their job provided them with adequate money to buy the things they wanted). What could be described as a sense of purpose and high self-esteem gained from employment was illustrated well by Katia (pseudonym) from AH who reported that her job was helping her to learn skills in selling as well as gaining patience:

Researcher: How do you find your job?

Katia: Good

Researcher: What sort of things are you learning?

Katia: Not to snap at people, get money, how to sell candles and flowers. Lots of money I get, I spend it on Saturday, sometimes I buy magazine, sweets.

	ADAM'S HOUSE	GREENLEAVES	MANN-WHITNEY U TEST	RAW EFFECT SIZE (R) ⁵
Beliefs& Practices (B&P)				
Mean	21.22	11.28	U = 69.000	-0.49
Median	20.50	8.00	p = 0.003**	
Range	6-30	0-29		
Support from spiritual community(SSC)				
Mean	10.56	5.83	U = 69.000	-0.49
Media	11.00	4.50	p = 0.003**	
Range	5-15	0-14		

Table 2 Service users' (n = 36) SBI-15R scores.⁴

Note: ** Significant at the 0.05 level; (n = 36) is the total number of participants.

	MEAN	MEDIAN	RANGE	MANN-WHITNEY U TEST	RAW EFFECT SIZE (R) ⁶
Satisfaction scale					
Adam's House	23.967	24.500	18-28	U = 97.500	-0.34
Greenleaves	21.714	21.500	13-26	p = 0.040**	
Competence/productivity scale					
Adam's House	21.389	25.500	12-29	U = 68.500	-0.49
Greenleaves	13.900	12.250	10-28	p = 0.002**	
Empowerment/independence scale					
Adam's House	21.750	21.550	18-28	U = 100.500	-0.33
Greenleaves	19.661	19.175	16-26	p = 0.051	
Social belonging/community integration scale					
Adam's House	23.200	23.000	19-29	U = 77	-0.45
Greenleaves	20.197	20.500	15-26	p = 0.006**	

Table 3 Service users (n = 36) QOL Questionnaire.

Note: ** Significant at the 0.05 level.

	BELIEFS & PRACTICES(B&P)	SUPPORT FROM SPIRITUAL COMMUNITY (SSC)
Satisfaction scale	rho = 0.339 p = 0.43	rho = 0.233 p = 0.192
Competence/productivity scale	rho = 0.636 p = 0.000	rho = 0.618 p = 0.000
Empowerment/independence	rho = 0.713 p = 0.000	rho = 0.559 p = 0.001
Social belonging/community integration	rho = 0.726 p = 0.000	rho = 0.715 p = 0.000

Table 4 Service users' (n = 36) Spearman Rho correlation for SBI-15R and QOLQ.

Note: ** Significant at the 0.05 level.

QOLQ empowerment/independence domain and SBI-15R

The empowerment/independence scores (see Table 3) for individuals from AH were slightly higher

than for those from GL in terms of having control over most aspects of their daily lives (e.g., how they spent their own money, activities they were involved in). The empowerment/independence scale was significantly

and positively correlated with SBI-15R's B&P and SBI-15R's SSC as displayed in Table 4. This seems to suggest that participants from both settings who indicated higher levels of spirituality and opportunities to practice spiritual beliefs, and who also gained more support from their spiritual community, reported that they were more empowered and independent than their colleagues.

QOLQ social belonging/community integration domain and SBI-15R

Significant differences in social belonging/community integration scores (Table 3) indicated that individuals from AH were involved in more social and communal activities (swimming; church; parties, dances, concerts), were very satisfied with these activities, and actively participated in them compared to those in GL. The social belonging/community integration scale was also significantly and positively correlated with SBI-15R's B&P and SBI-15R's SSC as illustrated in Table 4. As a result, individuals who reported higher spirituality and opportunities for spiritual practice and who gained more social support from their spiritual community were more likely to indicate that they belonged to more than three community organisations (including church or other religious activities) and were more likely to have friends/family over to visit them often. The significant and positive correlations found between the SBI-15R and the QOLQ domains were also qualified and corroborated by what individuals said in the more qualitative parts of the interview as illustrated in the thematic result below.

THEMATIC RESULTS: USE OF RELIGIOUS AND SPIRITUAL RITUALS

One main theme was inducted from the qualitative data. The theme 'use of religious and spiritual rituals' was common to both services and included two sub-themes: 'a sense of community' and 'a sense of peace'. These appear to demonstrate how residents in both AH and GL used religious and spiritual practices to meet their communal and psychological needs through church attendance and participation as exemplified below.

A SENSE OF COMMUNITY

The quotes below illustrate how participants enjoyed the communal and social benefits of church attendance. This further highlights the importance of religious and spiritual practices and participation for individuals with ID, often for communal and social gains as much as spiritual aspects, connecting persons with ID to friendships that are essential to feeling a sense of community and belonging:

'[in church] we sing, we have drums, guitar, piano and all that, and singers. And they give the word

of God, which is sometimes it's a little bit boring, but yea I really enjoy it. [I like] being with family, and just getting to meet up with my friends that I've not seen for a long time. we catch up, stuff like that, being as one big family.' Rose (AH)

'I like talking to God, sitting down and talk to him, talk to other people as well.' Katia (AH)

'like coffee break, oh...my church and many people go to church that's why I meet people... like people singing, oh God, singing, singing, how do I say, on church lots of people sing hymns songs, like go to service.' Paterson (AH)

Researcher: what makes you think he likes church?

'he is just so happy when he is there, when he sings the songs, although he can't read he is trying to look at the stories, they start off like 10 minutes in the church and they go off into their own little group, they have like stories if you like and colour in pictures and at home he sits and sings like this (prayer position), any other day it's him singing his church songs.' Staff member talking for Tyres (GL)

'he just goes to church because he likes the people rather than to worship. Then they have a cup of tea and biscuit before they go home; they are happy, smiling, definitely because of the atmosphere.' Staff member talking for Mikey (GL)

'he enjoys going to church and that, but I think more of the social aspect of the experience. I don't know, he doesn't read the bible or anything, he can't talk but he likes to go.' Staff for Bernard (GL)

'He...really enjoys it and sings and couple of the ladies come down every couple of months, from church, they come and meet him and do choir thing I think he went to church with his mum a lot he is always up for church on a Sunday and you can clearly see that that makes him happy, he smiles, might not say words or know but he will sing, it is difficult to assess if he is getting anything out of it but he is happy, but maybe triggers memory and sings some of the songs, like a little bulb coming gives him bits of memory back as he sings.' Staff for Jim (GL)

A SENSE OF PEACE

This second category, as emphasised by the below quotes, illustrates how participants valued the psychological benefits of church attendance and spiritual practices. These practices not only enable individuals to connect

with family and friends but also to connect with the transcendence, which seems to help them by yielding a sense of peace, especially through difficult times:

Researcher: How do you feel when you go to church?

'I feel happy, at peace, being with my family, my friends and just being with Jesus and worshiping Him, it makes me feel especially when am upset and sad I can just put on some Christian music and yea I really like singing and to Him, makes me all happy and alive inside.' Rose (AH)

'I just enjoy it [church]...I feel peaceful.' Charles (AH)

DISCUSSION

This study aimed to explore how spirituality related to the QoL perceptions of individuals with ID living in faith-based (AH) and a non-faith-based (GL) care service. The research question asked whether religious and spiritual belief in a supreme being and practices as well as social support gained from religious and/or spiritual affiliation contribute to the QoL perceptions of individuals with ID in two dissimilar residential settings.

The mean number of individuals in GL who reported a level of spiritual and religious belief and gaining spiritual as well as social support from the spiritual community was less than the mean number of service users reporting such beliefs and support in AH. Participants from AH recorded significantly higher mean and median scores on the QOLQ compared to their GL colleagues. It could be argued that our quantitative data seemed to mostly indicate how spiritual and religious beliefs and practices and support from spiritual community may have influenced participants' appraisal of some aspects of their QoL as found in research by Dezutter and colleagues (2010a; 2010b). Although further analysis indicated significant correlations between the SBI-15R spirituality measure and most of the QOLQ domains, this was an exception for the satisfaction scale, which did not significantly correlate with the SBI-15R. This appears consistent with some non-ID (e.g., Chlan, Zebracki & Vogel, 2011) and ID research (e.g., Büssing, et al., 2017) measuring the relationship between religiosity and spirituality and QoL that have found no and/or weak correlations with more religious-related items. However, the scales and modes of measurements used by Chlan, Zebracki, and Vogel (2011) and Büssing and colleagues (2017) differed from ours. For example, Chlan, Zebracki, and Vogel (2011) measured importance of religion using a Likert scale ranging from 1 (not important) to 5 (very important) and only incorporated 2 items related to the spiritual coping domain on the Brief-COPE in their

administration and analysis, which was found to correlate with life satisfaction. Büssing and colleagues (2017) only utilised the spiritual aspects of the Spirituality and Religiosity-Practices; Aspects of Spirituality, and Spiritual Needs Questionnaire measures, and even though they found that life satisfaction significantly correlated with the 'feeling that God is at one's side', other items such as 'praying', 'conscious interaction with others', and the perception that 'the heart is filled with joy' had very weak correlations with life satisfaction (Büssing, et al., 2017).

Contrary to Bigby and Beadle-Brown's (2018) review, which did not include spirituality as a possible factor that influences the QoL of people with ID, current qualitative data mostly seem to indicate that spiritual and religious beliefs and practices, as well as support from spiritual community, form an important part of participants' QoL perception. These are corroborated by other research (e.g., Bacon, 2021 (doctoral thesis); Biggs and Carter, 2016; Carter et al., 2014; Forrester-Jones et al., 2006; Sango and Forrester-Jones, 2019; Swinton, 2002), most of which have also found religious belief and practice to provide a sense of hope, comfort, and opportunity to engage in a social network. Our qualitative findings bore out the quantitative data, also highlighting how individuals from both services appeared to have an understanding of spiritual matters and the benefits spiritual and religious beliefs and practices had for their lives, consequently concurring with previous, though less detailed, ID research (see Baldwin et al., 2015; Büssing et al., 2017) and other non-ID literature (e.g., Bonelli & Koenig, 2013; Counted, Possamai & Meade, 2018).

Our qualitative results also highlight how some participants with ID find aspects of religious practice 'boring' or inaccessible in the context of sermons, though this may not be extraordinary to people with ID. It could be argued that there may be a need for more individualised and purposeful adaptations of sermons for a more diverse audience with varied learning needs. Overall, our modest study draws attention to the need for effective support for and inclusion of individuals with ID in spiritual/religious activities if they want these. We would also advocate Carter and colleagues' (2016) dimensions of belonging, such as 'being present, noticed, welcomed, accepted, supported, cared for, known, befriended, needed and loved', being adopted within religious services to help foster a sense of more inclusive community for individuals with ID and their families.

STUDY LIMITATIONS

Our study sample of 36 was small and gendered, consisting mainly of males. This makes generalisations difficult. However, the study included the majority of participants residing in the two care services and provided detailed accounts of the research background, which contextualises the study as a mixed-methods case

comparison (Creswell & Plano Clarke, 2018) with in-depth evidence to pinpoint recommendations for practice rather than attempting to yield generalisable findings. It is possible that some of the sample provided what they might perceive to be the most socially desirable answers to questions, especially when self-reporting, though we tried to mitigate this by triangulating the data, leading to increased data reliability (Creswell, 2013).

That our study was restricted to the Christian faith could be seen as a limitation. Whilst our initial intention was to include a range of faith traditions, and we spent a long time attempting to recruit services with a range of faith traditions including Jewish and Muslim, our efforts were unsuccessful—the main reason for non-participation being staffing issues. Buy-out of staff time to help with research projects is increasingly becoming difficult for services to justify due to squeezed budgets (Forrester-Jones et al., 2021), with the knock-on effect of limiting research.

CONCLUSION AND RECOMMENDATION

Our findings illustrate how spiritual and/or religious beliefs and practices and support from spiritual community can contribute to the QoL perception of individuals with ID. To deny people with ID the opportunity for spiritual and religious experiences and support could be argued to limit their legal right in relation to fulfilling all aspects of human life and achieving their highest level of personal development, similar to Maslow's self-actualisation hierarchy of needs. Even though the UN Convention on the Rights of Persons with Disabilities does not explicitly recognise this spiritual right (e.g., Whiting & Gurbai, 2015), other UN conventions do, and we recommend that health and social care professionals and organisations explore more ways to work with religious organisations and/or representatives (e.g., churches, chaplains, etc.) to facilitate quality spiritual and religious care provision for individuals with ID.

NOTES

- ¹ Pseudonym for faith-based service.
- ² Pseudonym for non-faith-based service.
- ³ More details of the settings are also reported in Sango and Forrester-Jones (2018; 2019).
- ⁴ The SBI-15R Table 2 derives from the larger study and is also reported in Sango and Forrester-Jones (2018).
- ⁵ We used Cohen's (1988 in Dunst & Hamby, 2012) effect size estimates for interpreting the strength of the relationship/effect size, where insignificant was up to 0.19, small was 0.20 to 0.49, medium was 0.50 to 0.80, and large was 0.80 onwards (see Dunst & Hamby, 2012).
- ⁶ We used Cohen's (1988 in Dunst & Hamby, 2012) effect size estimates for interpreting the strength of the relationship/effect size, where insignificant was up to 0.19, small was 0.20 to 0.49, medium was 0.50 to 0.80, and large was 0.80 onwards (see Dunst & Hamby, 2012).

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COMPETING INTERESTS

The authors have no competing interests to declare.

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