Spirituality and the Quality of Life of individuals with Intellectual Disability.

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Context: Spirituality seems to form part of person-centred care planning and needs assessment of persons with intellectual disability. Yet, the role of spiritually 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 belief and practice was linked to individuals' perception 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 a 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 were 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.

Keywords: intellectual disability, spirituality, spiritual/religious activities, quality of life, faith, non-faith.

Introduction

Quality of Life (QoL) is a complex (Alborz, 2017; Van Hecke, Claes, Vanderplasschen, De Maeyer, De Witte and Vandevelde, 2018) construct which has both subjective and objective interconnected components (Van Hecke et al., 2018; Bartelli, 2020). 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 (Narvaez et al., 2008) (e.g. work and education) as well as the physical and social environment (e.g., Schalock and Keith, 1993, p. 2; Nieuwenhuijse et.al., 2019). Whilst Hensel et al. (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 et al. (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 and Fernández, 2010) which include individuals with ID; social care services do not aim to treat impairments rather they endeavour to provide both functional and domestic support which include intimate tasks such as administering medications, 'washing' and 'dressing' (Malley and Fernández, 2010). Data from the independent regulator of health and social care in England, Care Quality Commission's website (CQC, accessed in May 2022), illustrates 1348 community services registered with CQC as of 2022, of these, 530 are ID community services (CQC, 2022). There are also 15001 care homes registered with CQC as of 2022, of these 5405 are ID care homes. There is currently no literature that gives an

overview of the number of faith-based care service providers in England. Approximately 37 out of the 5405 care homes registered with CQC across England are faith-based, 16 are affiliated with a Christian faith-based provider; 21 are associated with a Jewish service provider. Faith-based organisations refer directly or indirectly to spiritual and religious values as the guiding principle of their service provision (see Solari-Twadell and McDermott, 1999). Faith and non faith-based services are approved support service providers for people with ID, registered with their local authority and CQC. Faith-based providers are also registered charities as such they can receive donations from the public. Both faith and non faith-based services recruit staff from diverse background, faith-based services tend to also recruit volunteers in addition to paid staff while non-faith based services tend to recruit permanent and agency staff.

People with an intellectual disability (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, Ault et al. (2021) reiterating the importance of support for individuals to fulfil all aspects of societal life as a significant goal of the disability community. Having religious and/or spiritual quests may well be one of these important aspects for some individuals with ID. Yet research (e.g. Turner et al., 2004; Sango and Forrester-Jones, 2017); practice (see Carter, Biggs, and Boehm, 2016; Sango and Forrester-Jones, 2019; Bartelli et al., 2020) and policy (Sango and Forrester-Jones, 2014; Whiting and 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 and Gurbai, 2015).

Although a consensus as to what defines spirituality has yet to be reached, we adopted a multidimensional approach (see Sango and Forrester-Jones 2019, pp.150-151; 2017, pp.281-282; Hill et al., 2000; Garssen,Visser and Pool, 2021 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); and "meaning and purpose" (making sense of life, striving for answers). These dimensions can be rooted in one of two aspects of spirituality "religious spirituality" (i.e., social practices and expression of belief – church attendance, worship, prayer etc) or "non-religious spiritualty" (i.e., belief in supernatural without necessarily socially practicing, meditation, belonginess etc) (Sango and Forrester-Jones 2019, pp.150-151). Evidence in the fields of general health (Thune-Boyle, Stygall, Keshtgar and Newman, 2006; Dezutter et al., 2010a; Dezutter et al., 2010b; Chlan, Zebracki, and Vogel, 2011; Counted, Possamai and Meade, 2018; Coppola et al., 2021; Cherblanc et al., 2021) and mental health (Bonelli and Koenig, 2013; Forrester-Jones et al., 2018; Garssen,Visser and Pool, 2021) points 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 Swinton, 2002 ; Liu, Carter, Boehm, Annandale and Taylor, 2014 and Rambow's 2016 unpublished Master's thesis) 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 Forrester-Jones et al., 2006; Biggs and Carter, 2016; Sango and Forrester-Jones, 2019 and the doctoral thesis by Bacon, 2021). 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, Biggs and Boehm, 2016; Carter and Bohern, 2019) may be found through participation in shared spiritual practices and congregational activities, Hunter and Kivisto (2019) found strong allegiances to religious faith by young people with ID. A growing number of studies (e.g., Bassett, Perry, Repass and Silver, 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., in press). A recent study by 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, very few studies have purposefully measured the relationship between spirituality and quality of life 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 Bussing et al., (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, and 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 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 Bartelli et al. (2020). Bartelli et al found that of the 121 articles identified to be potentially relevant, upon further review only 44 of the 121 papers were useful in answering their review question related to the relationship between spirituality and QoL in people with ID. Bartelli et al argued that these 44 papers illustrated very low level of 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 question was: does religious and spiritual beliefs and practices relate to the QOL perception of individuals with ID in two dissimilar residential settings and 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 and Forrester-Jones, 2018; 2019). Though the methodologies and participants employed are the same, the findings and conclusions differ substantially with

[1] Pseudonym for Faith-based service

[2] Pseudonym for non-faith based service

the current submitted paper illustrating findings on how spirituality relate to the QOL perception of persons with intellectual disability.

Methods

Sample and setting

A purposive sampling method 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 as regards statements of faith. AH operated on a Christian philosophy and included 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, consisted of three residential houses (3-11 residents in each house) and was staffed via a 24-hour care system by paid carers who did not live in the homes. Whilst the two services were 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 of individuals with ID in two dissimilar residential settings in Southern England.

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 (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, Klassen, Plano Clark and Smith, 2011).

Schalock 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. Schalock 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 e.g., living arrangement, family, social settings etc.); 2.) Competence/productivity scale (i.e., employment-voluntary or paid e.g., skills learnt; ability to do their job well etc.); 3.) Empowerment/independence scale (i.e., decisions about aspects of their life, e.g., the activities they were involved in) and 4.) Social belonging/community integration scale (i.e., how involved they were within their communities, e.g., 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' to depict feelings of happiness, neutral and sad faces 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 consultation from 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, who 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, Lobley and Bozatzis, 1994). Participant-staff correlations, (i.e. resident's 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 the QOLQ Manual, Schalock and Keith, 1993, p. 19; Cummins, 1997).

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 quality of life. An analysis of SBI-15R by Holland et al. (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 the 15 items together.

Both the QOLQ and SBI-15R were administered via face-to-face semi-structured interviews with the measures forming the structured part of the semi- structure interviews. These commenced in the second month of the six months spent in each care service (6 months was spent in AH and another 6 months was spent in GL). This enabled the first author to integrate within the communities and build rapport as well as trust building with participants. Semi- structure interviews lasted between 15 to 40 minutes depending on the verbal capability of each participant. All audio-recorded data from interviews to administer the measures were 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 to test for any influence spirituality had on service participants' perception of their quality of life. Tables 2 and 3 indicated 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 process we familiarised ourselves with the data following transcription of audio, reading through transcribed texts and making initial notes. These data were then coded by highlighting parts of transcribed texts line by line and labelling these to describe their content. Patterns among the codes across the data were identified and used to generate the theme and subthemes found. These were reviewed by comparing them against the data set and ensuring that quotes pertaining to each theme and subthemes accurately embody the data, a spider map aided this process and the defining and naming of 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.

SERVICE USERS' (*N*=36) DEMOGRAPHIC DATA.

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

	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

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 and GL's spiritual and religious practices were either rooted in the Chrisitan or Catholic religion.

SERVICE USERS' (N=36) SBI-15R SCORES.

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

	Adam's House	Greenleaves	Mann-Whitney U test	Raw effect size (r)[3]
Beliefs & Practices				
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				
Mean	10.56	5.83	U=69.000	-0.49
Media	11.00	4.50	p=0.003**	
Range	5-15	0-14		

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

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 none for Empowerment.

SERVICE USERS (N=36) QOLQ.

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

	Mean	Median	Range	Mann-Whitney U test	Raw effect size (r)[4]
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**	

[3] 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" 0.20 to 0.49, "medium" 0.50 to 0.80, and "large" 0.80 onwards (see Dunst & Hamby, 2012).

[4] 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" 0.20 to 0.49, "medium" 0.50 to 0.80, and "large" 0.80 onwards (see Dunst & Hamby, 2012).

Competence/productivity scale					
Adam's House Greenleaves	21.389 13.900	25.500 12.250	12-29 10-28	U=68.500 p=0.002**	-0.49
Empowerment/independence scale					
Adam's House Greenleaves	21.750 19.661	21.550 19.175	18-28 16-26	U=100.500 p=0.051	-0.33
Social belonging/community integration scale					
Adam's House Greenleaves	23.200 20.197	23.000 20.500	19-29 15-26	U=77 p=0.006**	-0.45

Note: **Significant at the 0.05 level

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

	Beliefs & Practices	Support from spiritual community
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

Note: **Significant at the 0.05 level

QOLQ Satisfaction domain and SBI-15R

A finding of significant difference for satisfaction scale (see Table 3) indicates that participants from AH reported to be more satisfied with their life in general compared to those in GL. For example, individuals from AH reported to derive 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 revealed

that the Satisfaction scale was not significantly correlated with SBI-15R's Beliefs and Practices (rho=0.339; p=0.43) or SBI-15R's Social Support from Spiritual Community (rho=0.233; p=0.192). These data seem to highlight 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. Competence/productivity scale was significantly and positively correlated with Beliefs and Practices (rho=0.636; p=0.000) and Social Support from Spiritual Community (rho=0.618; p=0.000). 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, and 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.

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). Empowerment/Independence scale were significantly and positively correlated with Beliefs and Practices (rho=0.713; p=0.000) and Support from Spiritual Community (rho=0.559; p=0.001). 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. Social belonging/community integration scale were also significantly and positively correlated with Beliefs and Practices (rho=0.726; p=0.000) and Support from Spiritual Community (rho=0.715; p=0.000). As a result, individuals who reported higher spirituality and opportunities for spiritual practice and 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."* (GL staff member talking for Tyres)

*"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*." (GL staff member talking for Mikey)

"*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."* (GL staff for Bernard)

"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." (GL staff for Jim)

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 connecting 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 perception of individuals with ID living in a 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 perception of individuals with IDD in two dissimilar residential settings.

The mean number of individuals in GL who reported a level of spiritual and religious belief and to gain spiritual as well as social support both within their service and 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 current quantitative data seem to mostly indicate how spiritual and religious belief and practice and support from spiritual community may have influenced participants' appraisal of some aspects of their quality of life as found in Dezutter et al. (2010). Although further analysis indicated significant correlations between the SBI-15R spirituality measure and most of the QOLQ domains, this was however 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, and Vogel, 2011) and ID research (e.g, Büssing, et al., 2017) measuring the relationship between religiosity and spirituality and quality of life who have found no and/or weak correlations with more religious related items. However, the scales and modes of measurements used in Chlan, Zebracki, and Vogel (2011) and Büssing, et al. (2017) differed from ours. For example, Chan et al 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, et al. (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

'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 belief and practice and support from spiritual community forms an important part of participants' QOL perception. These are corroborated by other research (e.g Swinton, 2002; Forrester-Jones et al., 2006; Carter et al., 2014; Biggs and Carter, 2016; Sango and Forrester-Jones, 2019 and the doctoral thesis by Bacon, 2021) most of which have also found religious belief and practice to provide a sense of hope, comfort and 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 Bussing et al., 2017; Baldwin et al., 2015) and other non-ID literature (e.g., Bonelli and Koenig, 2013; Counted, Possamai and Meade, 2018).

Our qualitative results also highlight how some participants with ID at least find aspects of religious practice 'boring' or inaccessible (e.g., the sermon), though this may not be extraordinary to people with ID! It could however be argued that there may be need for more individualised and purposeful adaptation of sermons for a more diverse audience with varied learning needs. We would also advocate Carter et al.'s (2016) dimensions of belonging such as "being present, noticed, welcomed, accepted, supported, cared for, known, befriended, needed and loved" being adopted within religious services as helping to foster a sense of more inclusive community for individuals with IDD 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. Also, generalisation is not the goal of the findings from this study but for the findings to identify recommendations for practice. It is possible that some of the sample provided what they might perceive to be the most socially desirable answer 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., 2018) with the knock on effect of limiting research.

Conclusion and recommendation

Our findings illustrate how spiritual /or religious belief and practice 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 and Gurbai, 2015) other UN conventions do and we would recommend that health and social care professionals and organisations should 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.

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