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Psychosocial experiences of chronic illness in individuals with an intellectual disability: A systematic review of the literature

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Abstract

Background: Increased life expectancy has led to an increase in diagnoses of chronic illness in people with an intellectual disability; despite this increase, research about the psychological impact is rare. This review explored the psychosocial experiences of chronic illness in adults with an intellectual disability, revealing potential predictors and moderators of these experiences. **Methods:** Online databases were systematically searched to identify relevant literature, using predefined inclusion criteria. Of the 25,058 titles initially identified, 4 were included, that is, those collecting data on people with an intellectual disability and diagnosed with cancer (n ¼ 2), chronic pain (n ¼ 1) and diabetes (n ¼ 1). **Results:** Narrative synthesis of the data identified six themes, namely, delayed diagnosis, information, communication and understanding, negative psychological consequences, negative physical consequences, social perception and social support. **Conclusions:** There are unmet needs within this population, including a lack of assistance in understanding their illness. A substantial gap in the literature should be addressed through further empirical work.

Keywords

chronic illness, intellectual disability, psychosocial needs, systematic review

Background

The World Health Organization (WHO, 2012) defines chronic illness as a disease of long duration, generally with a slow rate of progression. It is estimated that chronic illnesses (including cancer that is classified as a chronic illness by WHO) represent 88% of all deaths in the United Kingdom (WHO, 2011); cardiovascular diseases (34%) and cancers (27%) are proportionately the largest causes of death. Receiving a diagnosis of, and living with, a chronic illness is distressing (Gunn et al., 2012; Musselman et al., 2003; Zabora et al., 2001); and in comparison with the general population, individuals with a chronic illness are more likely to suffer from depression and anxiety (Hinz et al., 2010; Rothrock et al., 2010). Psychosocial experiences are being explored more within chronic illness research, with unmet psychosocial needs being highlighted in various populations (Green and Smith, 2004; Harrison et al., 2009; Steed et al., 2003; Swash et al., 2014). Psychosocial needs relate to the individual and their interactions with their present environment (Oxford English Dictionary Online, 2014). Such needs, for instance, support, practical, psychological, physical or information needs, are essential aspects of one's psychological and social well-being in relation to health-care provision (Thewes et al., 2004). Research exploring psychosocial needs has been conducted in a variety of chronic illness populations, including diabetes (e.g. Barnard et al., 2012; Hood et al., 2014), cancer (e.g. Butow et al., 2012; Carlson et al., 2013; Hulbert-Williams et al., 2012) and chronic pain (e.g. Andersen et al., 2014; Jensen et al., 2011). However, there has been a relative paucity of research examining these issues among people with an intellectual disability.

The life expectancy of people with an intellectual disability is steadily increasing to a similar rate to that of the general population (Emerson et al., 2014), with some research suggesting that individuals with a mild intellectual disability may have a life expectancy similar to the general population (Puri et al., 1995). As life expectancy is likely to be increasing, so are diagnoses of chronic illnesses within this population (Hanna et al., 2011; Ryan et al., 2011; Tuffrey-Wijne et al., 2007). Whilst there are some indications that life expectancy and diagnoses of chronic illnesses are on the rise, the extent of current knowledge in this area is limited. Thus, the ability to make an accurate estimation of the number of individuals being diagnosed with a chronic illness, and subsequently the proportion of these individuals receiving a diagnosis as a consequence of an increased life expectancy, is problematic.

Individuals with an intellectual disability often have impairments in skill areas, including interpersonal communication skills, personal care, reading and knowledge (APA, 2013). These difficulties may disadvantage those with an intellectual disability when accessing health screenings and later diagnosis and treatment services. In the general population, chronic illness care generally follows a self-management framework (McCorkle et al., 2011; Newman, et al., 2004). Whilst health checks for people with an intellectual disability have been shown to be beneficial (Robertson et al., 2012), the self-management framework may not always be successful as people with an intellectual disability may not be aware of, or may ignore, their symptoms to a greater extent than the general population (Turk et al., 2012a) and uptake for health screening appointments is varied (Osborn et al., 2012). Communication barriers and a scarceness of accessible information (Ouellette-Kuntz, 2005; Tuffrey-Wijne et al., 2012; Wilkinson et al., 2011) may also contribute to this disadvantage.

Few empirical studies have explored the psychosocial impact of chronic illness on those with an intellectual disability. However, to inform priority areas for future research in this area, it is important to draw current knowledge together to (a) establish what is presently known and (b) identify gaps to inform future research design. This review was designed to identify, evaluate and synthesize literature exploring the psychosocial experiences of chronic illness in adults with an intellectual disability (including pre-diagnosis, diagnosis, treatment, survivorship and self-management phases). As a secondary research question, the review aimed to extract information on potential predictors and moderators of these experiences (e.g. social support and communication impairments) and to identify gaps in current knowledge that need to be addressed.

Method

From scoping searches, it was evident there was a paucity of literature. Systematic database searches were developed, therefore, to be sensitive rather than specific, ensuring maximum inclusivity of relevant articles (Petticrew and Roberts, 2006). By reviewing literature across all chronic illness diagnoses, it was anticipated that examples yielded from the management of one illness population could be applied to others (Higgins and Green, 2011).

Inclusion and exclusion criteria

The review was concerned with psychosocial experiences of adults with an intellectual disability and a chronic illness. Standardized inclusion and exclusion criteria were developed as follows: (a) all intellectual disabilities and chronic illness diagnoses were included, ensuring searches were comprehensive; (b) experiences at any time point were considered, including pre-diagnosis (e.g. routine screening), diagnosis, treatment, self-management, illness-free periods, progression, survivorship, palliative care and end of life; (c) child and adolescent samples were not included; (d) work could be retrospective or current; (e) the reporter could be the individual with an intellectual disability or a proxy; (f) qualitative and quantitative studies were included; and (g) studies were not required to use specific outcome measures or measurement tools.

Articles were limited to publications in English. Restrictions were not placed on date of publication, as a comprehensive overview of all research, historic and current, was required.

Database searches

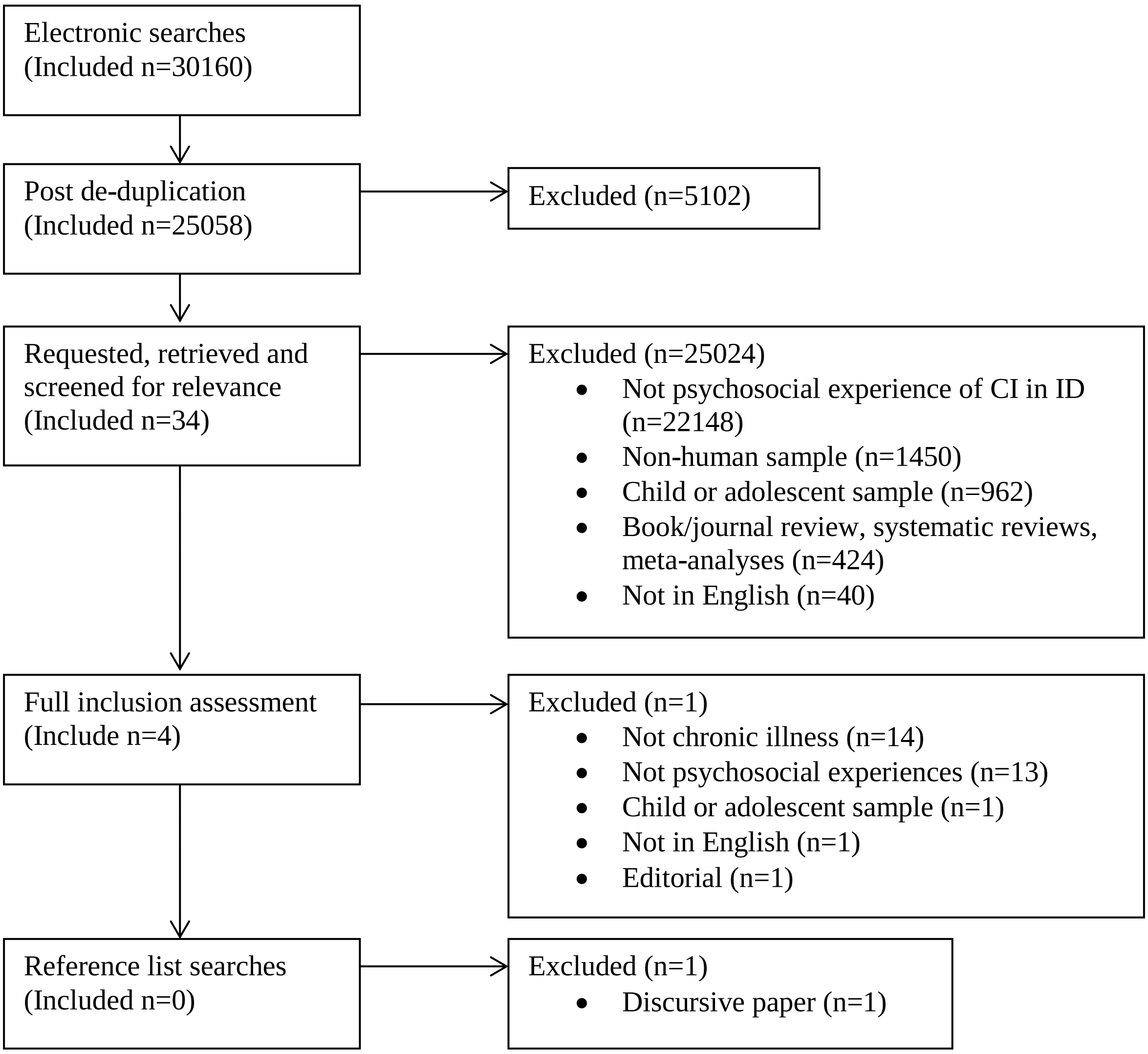
Online databases (CENTRAL, Web of Science, Medline, PsychINFO and CINAHL) were searched using three search strings, each including a comprehensive list of relevant terms (chronic illnesses, intellectual disabilities and psychosocial experiences). The online databases were selected in consultation with members of the research team who were experienced in conducting systematic reviews, including for the Cochrane Collaboration (Edwards et al., 2008). Terms for these search strings were identified using the existing literature, among other sources (e.g. Lazarus, 1991; Mencap, 2012; WHO, 2010, 2012). Search strings were developed in collaboration with the wider research team, for terms included within the search strings please refer to Appendix 1. Searches took place during December 2012.

Review strategy

From the searches, a total of 30,160 results were returned (see Figure 1). Automatic and manual de-duplication was undertaken. Post de-duplication, titles and abstracts of 25,058 studies were screened for broad relevance by one reviewer (1), with a 5% random sample (1215 abstracts) independently checked by another reviewer (2); this is an accepted practice when a review is large and resources are restricted (Petticrew & Roberts, 2006). Of the 1215 abstracts reviewed by both reviewers (1 and 2), it was agreed that 4 were eligible to undergo full inclusion assessment, along with 30 other abstracts identified within the other 95% by the first reviewer.

Full articles of these 34 abstracts were assessed for inclusion by two reviewers (1 and 3) independently, and articles that did not meet full inclusion criteria were discarded. Any disagreements were discussed and resolved in consultation with a third reviewer (2). A manual search of the reference lists of included articles was undertaken to locate any relevant articles not identified by electronic searches. One article was identified by these means; however, it was a discursive article and not eligible for inclusion in the review.

Fig 1. Flow chart indicating the narrowing of included papers



Data extraction and synthesis

Data extracted from the articles included sample description (details of participants' intellectual disability and chronic illness diagnoses), study design and key findings. Methodological quality assessments were also undertaken using the Framework for Assessing Qualitative Evaluations (FAQE) (Spencer et al., 2003) for qualitative studies, and the Kmet, Lee and Cook (2004) quality assessment checklist for quantitative studies. Some systematic reviews exclude poor quality studies

(Higgins and Green, 2011); however, given the paucity of literature in this area, provided that a study met all inclusion criteria, a poor quality assessment did not warrant automatic exclusion. The four studies included in this systematic review focussed on the psychosocial experiences of those diagnosed with: cancer (n=2) (Cresswell and Tuffrey-Wijne, 2008; Tuffrey-Wijne and Davies, 2006), diabetes (n=1) (Dysch et al., 2012) and chronic pain (n=1) (Lewis et al., 2007). Summaries of these studies are presented in Table 1.

Only one study presented quantitative data, thus a narrative literature synthesis was used as they are better suited to reviews of mixed methodology literature than meta-analyses (Popay et al., 2006).

Results

When studies were synthesised by psychosocial experience (Table 2), six themes of experience emerged. Studies are numbered (see Table 1) and will henceforth be referred to by these numbers.

Delayed diagnosis

Participants noticed a change in their health and sought advice from their general practitioner [1 and 4]. Physical symptoms prior to diagnosis were described, for example, the inability to eat properly due to the swelling tumour [1], a bad odour emanating from the tumour [4] and rapid weight loss [1 and 4]; however, participants were assured that their symptoms were innocuous [1 and 4]. One participant [1] sought advice when the symptoms progressed; however, she was again informed that she was in good health. In contrast, another participant [4] did not seek further medical attention, despite the progressive symptoms, concealing his declining health from his family. Both participants were eventually admitted to hospital in a critical condition [1 and 4].

Table 1: Summary table of methodology of included papers

	Authors	Year	Country	Sample size	Sample description	Design	Measures	Data analysis	Quality assessment score
[1]	Cresswell, A., and Tuffrey-Wijne, I.	2008	UK	1	A 30-year-old woman with cerebral palsy and an intellectual disability (unspecified), diagnosed with non-Hodgkin's lymphoma six years previously (unspecified stage): she received chemotherapy, steroids and radiotherapy.	Qualitative	N/A	None presented	FAQE: 3/36 (8.3%)
[2]	Dysch, C., Chung, M.C., and Fox, J.	2012	UK and UAE	4	Four people with mild intellectual disabilities and diabetes (Type 1 or 2). Participants had a mean age of 35 and were diagnosed with diabetes between 9 months and 33	Qualitative	N/A	Interpretative Phenomenological Analysis	FAQE: 30/36 (83.3%)

					years of age (one participant's age at diagnosis not stated within the paper).				
[3]	Lewis, S., Bell, D., and Gillanders, D.	2007	UK	1	A 32-year-old woman with a mild-moderate intellectual disability and chronic pain.	Quantitative	GAS-ID; GDS-LD, adapted FAPS; adapted PRCS	Not specified	Kmet: 5/28 (17.9%)
[4]	Tuffrey-Wijne, I., and Davies, J.	2006	UK	1	A 44-year-old man with cerebral palsy and a mild intellectual disability, diagnosed with advanced penile cancer; he underwent surgery to remove his penis, bladder and bowel.	Qualitative	N/A	None presented	FAQE: 5/36 (13.9%)

Table 2: Identification of themes within included papers

	Delayed diagnosis	**Information, communication, understanding**	**Psychological consequences**	**Physical consequences**	**Social perception**	**Social support**
[1]	✓	✓	✓	✓	✓	✓
[2]		✓	✓	✓	✓	✓
[3]			✓	✓		
[4]	✓	✓	✓	✓	✓	✓

Information, communication and understanding

The use of complex language by health-care professionals when explaining the diagnosis and treatment options was inhibiting and increased the levels of anxiety [1 and 4]. The complex nature of chronic illnesses was also challenging for the participants; some individuals attributed side effects to their recent behaviours rather than to their illness [2]. The use of accessible language both textually and verbally was conducive to understanding for the participants [1 and 4]. Some doctors accessibly explained the participant’s diagnosis [4]; however, there was a general lack of accessible communication from hospital staff [4].

Negative psychological consequences

Uncertainty was experienced about the current situation [1], their mortality [1 and 4] and whether the illness was lifelong [2]. Confusion about the condition [2] and distress about being different to others [2] were experienced by some participants, and one participant [4] reported that he concealed his emotions from his family. In one study [3], the negative psychological consequences of having a chronic illness were addressed and reduced; improvements were found in the Glasgow Anxiety Scale for people with an intellectual disability (GAS-ID; baseline = 38; month 2 = 26; month

4 = 18) and Glasgow Depression Scale for people with a learning disability (GDS-LD; baseline = 17; month 2 = 24; month 4 = 10). Scores for resourcefulness within the Pain-Related Control Scale (PRCS) improved (baseline = 3; month 2 = 2; month 4 = 6) and the score for helplessness was maintained (PRCS; baseline = 4; month 2 = 5; month 4 = 4). Having faith [4] was also reported to be associated with reduced negative psychological consequences.

Negative physical consequences

Physical consequences of treatment were hair loss [1] and altered sense of taste [1], and also included restrictions caused by the illness, such as monitoring blood sugar and following strict dietary controls [2] and undergoing physiotherapy to regain mobility post-surgery [4]. Due to the lasting physical effects of surgery, one participant [4] was unable to climb stairs and thus was unable to continue living in his home. It was found that post-intervention, one participant [3] was more physically able and active, less fearful of physical activity (Fear and Avoidance Pain Scale: baseline = 24; month 2 = 19; month 4 = 14) and had improved sleep.

Social perception

Participants were concerned about how others perceived the effects of their treatment, for example, illness management behaviours could be misinterpreted as drug misuse [2] and a side effect of treatment, vomiting in public, could be viewed as the individual being intoxicated [4]. Some participants were placed in older age wards or homes [1 and 4], which in turn had negative consequences on participants as neither felt that it was the right environment for them. One participant [1] reported that she was verbally abused by another patient, as the other patient did not understand her situation.

Social support

One participant [4] had feared family members’ reactions to his diagnosis but was being supported by them. Another participant [1] was unable to see friends whilst she was undergoing treatment, despite the lack of physical engagement with them she still felt supported. In contrast to this, the participants in another study [2] were aware of their need for support but often resented it.

Discussion

Review Findings in a Broader Context

Overall, the findings were relatively consistent between diagnoses, with findings within most themes overlapping significantly. This signals that although the diagnosis, subsequent treatments and consequences differ, the psychosocial impact of the illnesses is somewhat similar.

Delayed diagnosis. These findings correspond with the previous research. A delay in diagnosis may significantly impact the successful diagnosis and effective treatment of illness (Ashing-Giwa et al., 2010; Turk et al., 2012a). It has been found that discussing intimate topics with people with an intellectual disability can be uncomfortable for both the person asking the questions and the individual with an intellectual disability (Turk et al., 2012b), potentially leading to unmet information needs and impacting successful and timely diagnosis. People with an intellectual disability may also fall victim to ‘diagnostic overshadowing’, whereby health-care professionals make false assumptions that symptoms are not due to a physical complaint but as a result of their intellectual disability (Reiss et al., 1982); it is possible that this tendency was at play in studies [1 and 4]. Considering the psychosocial impact of delayed diagnoses, experiencing a diagnostic delay has been found to lead to psychological distress in the general population (Risberg et al., 1996).

Information, communication and understanding. These findings are consistent with the wider literature, as it has been found that accessible information is not always available for those with an intellectual disability (Ouellette-Kuntz, 2005; Tuffrey-Wijne et al., 2012; Wilkinson et al., 2011); this can exacerbate anxiety, fear and distress (Tuffrey-Wijne et al., 2010) as was the case within studies [1 and 4]. Chronic illness terminology is difficult to understand (Makaryus and Friedman, 2005); for those with an intellectual disability such terminology is likely to be even more challenging, potentially leading to substantial misunderstandings and unmet information needs. Whilst there is a plethora of chronic illness information available in the public arena (e.g. leaflets, websites and information centres), the information provided may not be accessibly written, thus leaving people with an intellectual disability unable to understand it (O’Regan and Drummand, 2008). Although it was found that participants did not always understand their diagnosis and the consequences of it [2], the subsequent provision of accessible information and communication assisted understanding [1 and 4]. Within the wider literature, it has been suggested that simple language (Tuffrey-Wijne and McEnhill, 2008; Turk et al., 2012a), pain indication screenings (Zwakhalen et al., 2004) and pictorial aids (Goodsell and Scarborough, 2006; Nind, 2008; Tuffrey-Wijne and McEnhill, 2008) may enable successful communication with those with an intellectual disability. Bromley et al. (1998) suggested that a combination of pictorial aids and pain indication screenings is most beneficial.

Negative psychological consequences. Receiving a chronic illness diagnosis is a distressing experience (Gunn et al., 2012; Musselman et al., 2003; Zabora et al., 2001). All articles within this review found that the participants were experiencing negative psychological consequences of their illness. People with a chronic illness have been found to feel guilt, shame (Person et al., 2009), responsibility (Mak et al., 2007) and embarrassment for having the illness and being different to others (Conrad et al., 2006); these feelings were evident within the articles in this review. A review of psychological adjustment to chronic illness suggests that patients should engage in selfmanagement strategies and express their emotions (de Ridder et al., 2008). However, this may not always be successful within an intellectual disabilities population, it has been found that those with an intellectual disability may express emotions in an unfamiliar way (Adams and Oliver, 2011); this may impact their psychological adjustment to a chronic illness diagnosis and the appropriate response by health-care teams.

Negative physical consequences. Symptomatology is inevitably similar for those with and without an intellectual disability; however, they may present particular problems for those with an intellectual disability; disability, for instance, not fully understanding the cause of the physical consequences and attributing them to unrelated events [2]. Whilst it is entirely possible that such instances may occur for those without an intellectual disability, conclusions cannot be drawn without further exploration into this area. Such misunderstandings about physical consequences may impede the individual’s ability to fully recognize their diagnosis, obstructing acceptance. It has been found that acceptance is an important stage in the illness trajectory and is related to psychological well-being (Karademas et al., 2009; Lewko et al., 2007).

Previous research has shown that the physical consequences of chronic illnesses and related treatments can lead to increased levels of anxiety, stress and depression (Katon, 2003), which may in turn lead significantly to more chronic illness symptoms being reported by the individual in question (Katon et al., 2007).

Social perception. It has been found that having a chronic illness can be stigmatizing (Earnshaw and Quinn, 2012); for instance, if the person is required to self-administer medication in public (Schabert et al., 2013). Within this review, perceived negative social perceptions as a result of diagnoses and treatment side effects were apparent within three of the articles [1, 2 and 4]. It is possible that there is an additional stigma present because of having an intellectual disability (Beart, 2005; Cooney et al., 2006); this stigma has been found to be detrimental to the wellbeing of those with an intellectual disability (Jahoda et al., 2010). It is not yet clear as to how the two forms of stigma interact and whether chronic illness stigma is worse in those with an intellectual disability than within the general population; this area requires further exploration.

Social support. Communication and social support are important moderators of chronic illness adjustment (Stanton et al., 2013). Individuals with an intellectual disability do not always have someone available for this (Tuffrey-Wijne et al., 2006, 2012). Whilst participants in three of the studies were receiving support, it was sometimes not sufficient [1], resented [2] or increased anxiety [4]. Social support has been found to be an important factor in psychological adjustment to chronic illness (White et al., 1992); often support is sought through peer (Embuldeniya et al., 2013; Flynn et al., 2013) and online support groups (van Uden-Kraan et al., 2008). It is possible that such avenues of support are not as readily available and accessible for those with an intellectual disability (Lippold and Burns, 2009), and this could lead to further feelings of isolation.

Predictors and moderators

In one study [1], it was found that the social support received was a moderator of negative emotions, with the participant highly valuing the support she received. Within the general population, it has been found that perceived social support moderates the relationship between cardiovascular disease and depression (Greco et al., 2013). Additionally, the participant [1] stated that having faith lessened the negativity that came with her cancer diagnosis. Similarly, in the general population, spirituality has been found to assist adjustment to chronic pain (Büssing et al., 2009).

Within this review, only one article [3] actively attempted to decrease the negative psychosocial experiences of chronic pain; this was a case study and as such it is imperative that future research employs a larger sample when exploring potential moderators and interventions.

Methodological summary and critique of included papers

The quality of qualitative articles was assessed using the FAQE (Spencer et al., 2003). Articles would score highly on the FAQE if it was clear how researchers reached their conclusions, and findings should be contextualized in relation to the existing, and future, research. The quality of the discussion of limitations, study design rationale, sampling strategy and how recruitment and data collection were carried out also impact the FAQE score. Finally, it is important to have a clear narrative to the article, employing reflexivity and providing a clear explanation of the research process. Using the Kmet, Lee and Cook (2004) quality assessment checklist for quantitative research, articles should outline a clear objective, the study design should be clear and appropriate and outcome measures should also be clearly defined and justified in order to score highly. Additionally, analytic methods, sample characteristics, estimates of variance and results should be described in sufficient detail to fully inform the reader. Lastly, conclusions should be fully supported by the results.

Study design. Both qualitative and quantitative methods were used; two qualitative articles [1 and 4] were purely descriptive accounts, in the case-study tradition, and did not present any substantial data analysis. Such publications serve to highlight the issue and are often a first step in developing impetus in researching a topic in intellectual disabilities (cf. Hulbert-Williams and Hastings, 2008). Whilst simply having data published in any form is of great importance, there are few robust conclusions to be drawn from the case study designs. The one qualitative study that undertook data analysis [2] was of good quality as assessed by the FAQE (Spencer et al., 2003) and was reported to be of high standard. Whilst one study [3] reported quantitative results, it did not report the analysis methods undertaken as part of the research, similarly effect sizes and significance levels were not reported; and this makes determining the weighting of the findings problematic.

The quality of the articles varied (see Table 1), with three articles [1, 3 and 4] receiving scores of less than 20%; had these articles been excluded, only one would remain. This highlights a need for more, high-quality, research to be conducted in this area; with increased confidence in the results of empirical research, further advances can be made in practice.

Sampling. All included studies had small samples, with three [1, 2 and 4] pertaining to one participant, and the remaining article [3] involving four participants. Whilst the findings do have implications for research, policy and practice, without substantial sample sizes and replication studies, it is difficult to influence policy and practice and to make practical use of the information gleaned from the research. Small sample sizes can also inhibit the extent of exploration within a study [2]. In one study [2], caregivers withdrew participants but the reasons for withdrawal are not discussed; data relating to reasons for withdrawal should be collected in order to inform future methodological designs.

Data collection. All articles received ethical approval from the appropriate bodies, and informed consent was obtained prior to the commencement of the research. In two articles [1 and 4], participants waived their right to anonymity, and in the other two articles [2 and 3], participants were given pseudonyms.

Methodological critique of this systematic review

Only four studies were identified for inclusion in this review, with a total sample of seven participants; whilst this is fewer than expected, and does limit the generalizability of the results from the review, it emphasizes the need for more empirical research being conducted within the area.

The search terms were collaboratively devised by all members of the research team, with attention being paid to inclusivity of terms; the researchers made every effort to ensure that all relevant terms were included within the search strings. It is however possible that some degree of bias may have operated when devising these terms.

Conducting a systematic review within an emergent field can call attention to an absence of research, facilitating further exploration (Petticrew and Roberts, 2006); whilst few studies were reviewed, a substantial gap has been highlighted as well as the need for further investigation.

Recommendations for future research

The review highlights a substantial gap in our knowledge of how people with an intellectual disability respond and adjust to diagnosis of a chronic illness, that is, further exploration of this topic would be beneficial, particularly, studies exploring a comprehensive range of type and severity of intellectual disability. It would also be interesting and helpful to those working in the health-care setting to discover what the specific needs of those with an intellectual disability are, exploring whether the standard support received (e.g. health education and clinical and social support) is fulfilling the needs of those with an intellectual disability or whether more needs to be done to achieve this. Further exploration of currently available information sources would also be warranted, potentially leading to suggestions for future improvements. Possessing a more coherent understanding will enable appropriate services and resources to be provided to fully meet the needs of people with an intellectual disability and a chronic illness.

Whilst research exploring the nature of psychosocial experiences in this population is always valuable, the articles within this review were of variable standard, making it difficult to fully appreciate these important findings. As such, it is imperative that there is a consistent high-quality research exploring this area further, and interventional research that attempts to reduce the effects of such experiences is arguably of most value. It is also important to understand the effectiveness of such interventions so that not only the best services are provided but ineffective interventions are not implemented. It is essential that people with an intellectual disability are involved in the design of the intervention to ensure that they are relevant and accessible (Nind, 2008). Not only is it important that the research is of high quality, but it is also crucial that the reporting of results is of the highest possible standard. The transparent reporting of analysis methods, effect sizes and significance levels should be included so that the weight of the findings can be fully established and concrete conclusions can be drawn.

Implications for practice, care and support provision

Whilst only little was found within this review, new ideas and research questions have been discovered. It is imperative that health-care professionals are mindful of the Mental Capacity Act 2005 and ensure that all individuals are helped to fully understand their diagnosis, the consequences of it and any treatment options that may be available to them. With the appropriate support (e.g. simple language and visual stimuli), many people with an intellectual disability, who may initially be deemed to not have capacity to consent, will be enabled to play an active role in their treatment experience. As a matter of standard practice, reasonable adjustments should be made in accordance with the Equality Act 2010; this is to ensure that the experience is no more difficult than it would be for someone without an intellectual disability. It is evident that the lack of accessible information conveyed both verbally and textually is distressing for those with an intellectual disability and can lead to confusion about their illness. It is, therefore, vital that information is provided in a form that is most understandable to the individual; this may vary from person to person. An adapted needs assessment, as is commonly used within the general population (Webster et al., 2003), should be explored, adapted and implemented among the population with intellectual disabilities.

Conclusions

This review has highlighted the paucity of empirical research being conducted into the psychosocial experiences of people with an intellectual disability and a chronic illness. Such research is being continually conducted within a general population sample; however, those with an intellectual disability are often overlooked. In general population psychosocial oncology, for instance, there is an emphasis on listening to the needs of the patient group and providing services dependent upon the findings (Corner et al., 2006). People with an intellectual disability are under-represented and very little is known about their experiences of chronic illness. It is imperative that we understand chronic illness experiences from a first-hand perspective in order to provide a high standard of care to this population. Additionally, it is of great importance that the data collected in collaboration with people with an intellectual disability, as it has previously been found that information provided by caregivers is often inconsistent with the information from the participant themselves (Turk et al., 2012a).

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