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REVIEW ARTICLE

Pharmacists' medicines-related interventions for people with intellectual disabilities: a narrative review

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Abstract *Background*People with intellectual disabilities (ID) have complex pharmaceutical care needs due to a high prevalence of multimorbidity, a notable degree of polypharmacy and a high risk of adverse drug reactions. Despite this, people with ID often experience significant health disparities compared to the general population. In most developed countries, increasing emphasis on deinstitutionalisation and community integration also means greater utilisation of primary health care services where general practitioners, pharmacists and carers may lack appropriate information about the pharmaceutical needs of this population. Aim of the review To explore what type of pharmaceutical care interventions were being undertaken for people with ID and how pharmacists' contributed to the care of people with ID as part of multidisciplinary teams. *Method* Systematic searches of the following electronic databases were carried out; CINAHL, Pubmed, Medline, Embase, Cochrane library, Science Direct and International Pharmaceutical Abstracts. Results were limited to the period 1994–2014 using search terms 'learning disabilities', 'intellectual disabilities', 'mental retardation', 'developmental disabilities', 'learning difficulties' and 'pharmacist intervention', 'pharmaceutical care', 'primary care', 'pharmacy' "pharmacists" "pharmacy technicians". Agreement on studies to be included was arrived at by consensus and by using a pre-determined set of inclusion criteria. Due to the heterogeneous nature of the study aims, methods and presentation of study outcomes found, a narrative review was considered appropriate. *Results* In total, after removal of duplicates, 70 abstracts were identified and screened from the initial search. After screening and consensus agreement, eight articles which met the inclusion criteria were included in the review and were analysed under the following three themes; pharmacist interventions, pharmacists collaboration in provision of care, qualitative studies relating to patient, carers, and pharmacist views on care of people with ID. *Conclusions* The limited evidence available in the literature suggests that pharmacists can make positive interventions in relation to the quality of the medication use process, in collaboration with other healthcare professionals, carers and patients with ID. However, further research will be required to increase the evidence base with regard to the benefits of providing pharmaceutical care to patients with intellectual disability and to inform future policy and planning.

Keywords Pharmaceutical care · Intellectual disability · Pharmacist · Pharmacist interventions · Clinical pharmacy

Impacts of findings on practice

- Pharmacist can have a positive effects on care of people with intellectual disabilities, promoting patient safety and improving the quality and appropriateness of medication use.
- Further research is required to strengthen the evidence base for pharmaceutical care interventions in this population.

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- Further education and training for pharmacists in interventions in people with intellectual disabilities, would benefit pharmacy practice.
- Pharmacists' organisations need to create the awareness that pharmacists have the skills and capacity to become fully integrated members of the primary healthcare team in the care of people with intellectual disabilities.

Introduction

Intellectual disability is "a disability characterised by significant limitations in both intellectual functioning and in adaptive behaviour, which covers many everyday social and practical skills. This disability originates before the age of 18." [1]. Other less widely used terms include 'learning disability', 'developmental disability' and 'mental retardation'. There are significant health disparities between people with intellectual disabilities (ID) and the general population [2, 3], and although life expectancy for people with ID has increased, premature mortality is greater than the general population [4, 5]. A number of reasons have been suggested; neurological and mental health problems often occur concurrently [6–8], and people with ID often present with secondary medical conditions, including epilepsy, visual problems, dental problems and thyroid conditions [2, 7, 9–11] resulting in a reported prevalence of up to 50 % more health problems that the general population [12]. In addition, diagnosing, treating and managing health conditions and ensuring appropriate healthcare access in this population is challenging due to difficulties in communication and poor knowledge and understanding on the part of health care providers or "diagnostic overshadowing" [6, 13].

People with ID have a substantial burden of disease and are frequently exposed to polypharmacy and the prevalence of psychotropic use has been reported to range from 40 to 44 % for long-stay hospitals or institutional settings, to 32 % for community based residential care and 9–10 % for those living in independent settings [14–17]. Furthermore, this population may be more vulnerable to side effects associated with these therapies, but because of communication difficulties are less able to report them [18, 19].

A case-controlled study among people with intellectual disabilities who were matched with people with of the same age and gender with no intellectual disability demonstrated that people with ID visited GPs 1.7 times more frequently and received four times the number of prescriptions compared to the general population [20]. Studies carried out in other vulnerable patient populations affected by polypharmacy have shown pharmaceutical interventions to be effective in reducing inappropriate prescribing and improving patient outcomes in nursing homes [21]. People with ID could benefit significantly from the provision of pharmaceutical care. In Primary Care, people with ID and their carers carry more of the responsibility for administering/taking medicines and for recognising and managing side effects, yet little is known about their attitudes to medicines, their interaction with pharmacists and their ability to engage in the health care process in primary care.

Deinstitutionalisation of people with ID began between the end of the 1980s and the early 1990s depending upon country [22]. Therefore people with ID are now utilising primary care services at a greater frequency. However, primary care health professionals may not have the specialist knowledge or practice experience of the unique issues to care for people with ID as they age [23]. From 1990 Pharmaceutical Care prompted pharmacists to reconsider their role and this process is still ongoing; in 2013 this concept was reworded as "the pharmacists' contribution to the care of individuals in order to optimize medicine use and improve health outcomes" [24]. Pharmaceutical Care also requires collaboration with other disciplines when the patient's care needs are complex but this type of collaboration is harder to achieve in primary care. People with ID are a vulnerable group who have need for pharmaceutical care.

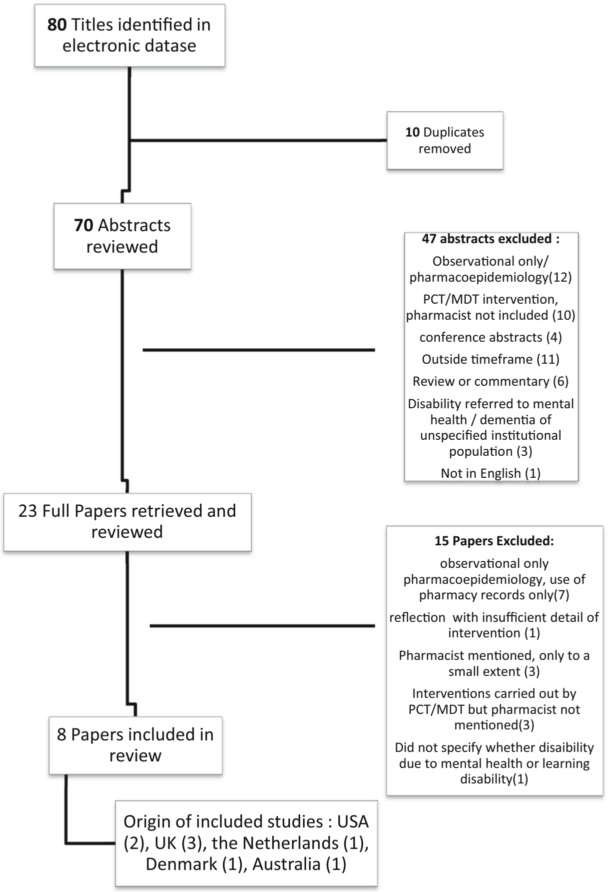

Fig. 1 Flow chart of included studies

Aim

Our aim was to explore the interventions pharmacists have implemented to improve the care of people with ID.

Our objectives were to determine; (1) What interventions have been carried out by pharmacists in relation to the care of people with intellectual disability and what outcomes have been used to measure this care? In which settings have the interventions been carried out? Have the interventions been carried out in collaboration with other healthcare professionals? (2) Are pharmacists playing a role as part of multidisciplinary panels in informing policy and decisions relating to service provision in relation to guidelines on the care of individuals with intellectual disabilities? (3) What are pharmacists' attitudes and opinions in relation to their role in the provision of care to people with intellectual disabilities? (4) Are there any studies that examine the experiences and/or views of patients or carers on the role of the pharmacist?

Method

Search strategy

Systematic searches of the following electronic databases were carried out by one author (M O'D); CINAHL, Pubmed, Medline, Embase, Cochrane library, Science Direct and International Pharmaceutical Abstracts. Results were limited to the period January 1994–August 2014. Search terms used for each database included: 'learning disabilities', 'intellectual disabilities', 'mental retardation', 'developmental disabilities', 'learning difficulties' and 'pharmacist intervention', 'pharmaceutical care', 'primary care', 'pharmacy' "pharmacists" "pharmacy technicians". References from identified journals were also screened to identify further relevant material (snowball approach). In addition, websites relating to policy matters on intellectual disability were screened to identify any further published relevant studies. Titles of all studies identified from the initial search were screened by two pharmacists (MOD, MH) and an independent expert (AM) and all the authors separately examined the lists of titles and abstracts and papers from the searches, and comparisons were made in relation to inclusion/exclusion lists. Hard copies were obtained for all papers that were considered for inclusion. Agreement on studies to be included was arrived at by consensus (Fig. 1).

Inclusion and exclusion criteria

Studies were included if they; (1) Described pharmacist's interventions and/or measured the outcome of the intervention in patients with intellectual disabilities, (2) described or evaluated service provision including pharmacy services for patients with ID or (3) included or described pharmacists' involvement on multidisciplinary panels in formulating guidelines for medicines for use in patients with intellectual disabilities. (4) explored pharmacists' knowledge or opinions relating to provision of care to people with intellectual disabilities. (5) made reference to the opinions/perceptions of patients with intellectual disabilities or their carers to the role of the pharmacist in providing information about medicines.

Studies were excluded if they; (1) made reference to interventions carried out by the primary care team or multidisciplinary/psychiatric team but the pharmacist was not mentioned as part of this team, (2) only referred to pharmacist's involvement in policy, organisation or administration of services as opposed to the provision of care, or, for example, if pharmacy records only were utilized for the study or the study was observational (3) were not in the English language (4) were outside the pre-determined timeframe, (5) were conference abstracts.

Abstracts from papers that met the initial inclusion criteria were then reviewed by the authors and full texts of relevant papers were then considered for inclusion by discussion. A narrative review was considered appropriate since the study aims, the methods used and presentation of study outcomes were heterogeneous.

Data extraction

Studies were analysed and categorised according to study aims, design, setting and participants, outcome measures and findings in a matrix format (Table 1).

Assessment of quality

Due to difficulties with capacity to consent the population with ID rarely participate in RCTs [25] and having an intellectual disability is often an exclusion criterion for participation. Therefore, our strategy was to identify and include all studies whether experimental, observational or descriptive and to comment on the quality.

Results

As schematized in Fig. 1, 70 abstracts remained after duplicates were removed, but only eight studies met the inclusion criteria. All studies except one [26] were published after 2000. Two countries provided most of the studies; USA (two studies) [27, 28]; UK (three studies) [26, 29, 30]; Netherlands (one study) [31] Australia (one study) [32], Denmark (one study) [33].

Table 1 Matrix of Publications Included

Publication details, country	Study aim(s)	Study design	Study setting and participants	Outcome measures	Findings
Pharmacist interventions					
Idzinga JC, de Jong AL, van den Bemt L The effect of an intervention aimed at reducing errors when administering medication through enteral feeding tubes in an institution for individuals with intellectual disability *Journal of Intellectual Disability Research 2009 Vol 53 932–938* The Netherlands	To assess the effect of providing pharmacists with information about patients receiving medication via enteral feeding tubes and of pharmacist education of nursing staff on medication error rates	Observational prospective study with pre- and post-intervention measurement of medication administration errors	Pre- and post-intervention measurement of medication administration errors through enteral feeding tubes to patients with intellectual disabilities from a sample of individuals in an institution in the Netherlands using a disguised observation technique. Medication was provided to the institution by community pharmacists. In the pre-intervention phase pharmacists did not know which patients were receiving their medication through enteral tubes. The intervention consisted of pharmacist education to those administering the medication and special labelling and directions on any medications that were being administered through enteral tubes	Number of medication administration errors observed pre- and post-intervention	During the pre-intervention period 245 medication administrations to six clients were observed over a period of 3 weeks. Post-intervention 229 medications administered to five clients were observed. Pre- intervention 158 (64.5 %) medication admin errors were observed, post-intervention 69 (30.1 %) medication administration errors was observed. The intervention programme was responsible for a reduction of over 50 % in medication errors
Thomsen L, Rossing C, Trier H, Faber M, Herborg H Improving Safety in the Medicines Use Process for Disabled Persons in Residential Facilities. Results from a Pilot Study J Biosafety Health Educ. 2014;2(114):2332–0893.1000114	The study had two main aims; 1. To raise awareness and improve knowledge on medication safety issues in settings for the disabled and 2. To examine whether existing pharmacy services in the settings can be expanded and delivered by community pharmacists within the facilities to improve medication safety	Descriptive study of community pharmacist interventions in quality improvement to support care staff in medication use and to provide medication review service. In design the study was explorative and "formative" (learning orientated)	Study of a medication review service carried out by community pharmacists to patients with intellectual disabilities, physical disabilities or severe mental illness within four residential facilities in Denmark (63 % of patients in the study had a physical and/or intellectual disability), convenient sampling Patients were identified as requiring a medication review by staff, pharmacists carried out the review, identified drug therapy problems and made appropriate suggestions. A Quality assurance service was also carried out in the institutions by pharmacists to identify issues regarding drug handling in the institution	1. Number of reviews carried out by pharmacists 2. Number of drug related problems identified 3. Number of suggestions relating to drug therapy made to the prescriber 4. Number of suggestions that were accepted by the general practitioner 5. Number of multidisciplinary dialogues that took place 6. Number of suggested changes made to the drug handling procedures in the institutions 7. The combined intervention: physicians, pharmacists and staff, carer's relatives and patients satisfaction with service	47 reviews were carried out by pharmacists On average the residents used 5.2 drugs and 2.3 drugs as required 30 residents were identified as having 66 drug related problems. 36 suggestions were made to general practitioners, 19 of these suggestions were accepted, 3 were rejected and 14 not responded to One multidisciplinary dialogue was carried out between the pharmacist, patient, nurse, psychiatrist and general practitioner Pharmacists suggested 45 changes to drug handling routines in the four institutions The new service was well accepted by pharmacists, doctors, family, staff and physicians

Table 1 continued

Publication details, country	Study aim(s)	Study design	Study setting and participants	Outcome measures	Findings
Pharmacist collaboration in service provision					
Brahm N, Brown R Clinical Pharmacology Services: A Pharmacist-based consulting service for the developmentally disabled *American Journal of Health System Pharmacy, 2004 61:487–492* USA	To describe the activities of clinical pharmacists in a disability service and to illustrate the impact of their activities on prescribing patterns	Observational, descriptive study	The introduction and implementation of a clinical pharmacy service available to all patents registered on the Oklahoma State Developmental Disabilities Services Department (DDSD) was described Participants were any registered patient in the community or in an institution identified as requiring a medication review or other clinical pharmacy service This clinical pharmacy service is a service unit of the Oklahoma College for Pharmacy and includes three clinical pharmacists Services carried out include drug therapy reviews and consultations, attendance at multidisciplinary meetings at institutions as medication experts, provision of education to nurses and other staff members in institutions. Also drug efficacy reviews to inform future policy. The pharmacy service also compared rates of prescribing of psychotropic medication between 2 months; January 1997 and October 2001. This was carried out retrospectively using prescription data from the databases of DDSD	Number of clinical pharmacy consultations that took place Rates of psychotropic prescribing in Jan 1997 compared October 2001	In 2001–2002 the clinical pharmacy service provided 929 institutional reviews during the course of 209 meetings The analysis of prescribing rates was carried out retrospectively 755 class members were identified for review. In Jan 1997 the overall rate of psychotropic medication was 17.9 % and it was 15 % in October 2001 Since the implementation of the services the rates of psychotropic prescribing have been reduced. In particular there had been a notable reduction in the use of anxiolytics, rates of anxiolytic prescribing was 4 % in 1997 and 0.7 % in 2001

Table 1 continued

Publication details, country	Study aim(s)	Study design	Study setting and participants	Outcome measures	Findings
Schmidt E, Byars J, Flamuth D, Schott J, Sever C Prevalence of Low Bone Mineral Density among Mentally Retarded and Developmentally Disabled Residents in Intermediate Care *The Consultant Pharmacist Journal, 2001 Vol 1A No. 1* *USA*	To assess the effect of pharmacist medication recommendations in an at risk population of low bone mineral density	Cross-sectional study	241 residents of intermediate care facilities for those with intellectual disabilities and of group homes at risk of low bone mineral density were included. From PIXI scan results analysis and examination of other risk factors, consultant pharmacists made pharmacotherapy suggestions based on current recommended guidelines. Pharmacists also correlated certain medications with an increase in the risk of low bone mineral density	Prevalence of low bone mineral density in the study population (from the PIXI scan results) in the osteoporosis or osteopenia range Number of non- traumatic fractures experienced in the study group 18 months post-intervention Identification of secondary causes if low bone mineral density e.g. medicines associated with bone density loss Number of patients in the study group that received the pharmacotherapy recommended by the pharmacist. 18 months after the study the number of patients in the study who had experienced non-traumatic fractures was assessed	157 participants (65 %) had PIXI scan results in the osteoporosis range. 32 (13 %) had results in the range for osteopenia range. Incidence of documented non -traumatic fractures 18 months post intervention in the study group was 3.5 % Based on the pharmacotherapy suggestions made by pharmacists 12 (29)% of the group received antiretrosorptive therapy with alendronic acid 10 mg once daily. 1.7 (4)% received salmon- calcitonin nasal spray (recommended if alendronic acid not suitable), 51.5 % (124) received Calcium 500 mg with Vitamin D (200IU) Among patients whose results indicated bone mineral density in the osteoporosis range 13.7 (33)% were taking phenytoin, 12 (30)% were taking carbamazepine. Pharmacists were able to identify patients requiring therapy and were able to follow guidelines in making recommendations as to the appropriate therapy. However only a small number of these suggestions were implemented by the doctors. Medications associated with bone mineral density loss were identified (the antiepileptics in particular)

Table 1 continued

Publication details, country	Study aim(s)	Study design	Study setting and participants	Outcome measures	Findings
Parkes C, Hasioh S, Samuels S, Hassiotis A, Lunggaard H, Hall I Incorporating the views of service users in development of an integrated psychiatric service for people with learning disabilities. *British Journal of Learning Disabilities 2007, Vol 35 23–29* UK	To obtain and incorporate the views of service users in the design of an integrated psychiatric service	Before and after assessment of impact of pharmacist counselling and advice. Qualitative study (semi-structured interviews)	Semi- structured interviews with individuals with intellectual disabilities. Two phases of interviews were carried out; phase one interviews with 12 individuals with intellectual disabilities on their experiences of admission into a general psychiatric facility in the last 3 years. Phase two-interviews with 19 patients on their view of care in a new dedicated four bed specialist facility for people with intellectual disabilities within a 16 bed psychiatric ward in an inner city hospital. There was a dedicated pharmacist in the new facility that was available to distribute specialised written material to the patient and verbally counsel the patients about their prescribed medications	Patients opinions or experiences in each phase of 1. Admision to hospital 2. Life on the ward 3. Nursing care 4. Patient knowledge and opinions on medical treatments	The majority of patients in both phases said they remembered someone explaining their medications to them Patients demonstrated a greater knowledge of their prescribed medications in the phase two interviews. Patients in phase two mentioned how useful they found the special information leaflets about the medicines Over half the participants in phase two understood the importance of taking their medications
Qualitative studies					
Di Blasi A, Kendell S, Spark MJ Perspectives on the role of the community pharmacist in the provision of healthcare to people with intellectual disabilities: explorations of the barriers and solutions *International Journal of Pharmacy Practice 2006, Vol 14 Issue 4 263–269* *Australia*	Assessment the perceptions of community pharmacists of their role in the care of people with ID, barriers to optimal provision of that care and solutions	Descriptive, qualitative study using semi-structured face to face interviews	Purposeful sample of 10 community pharmacists from a region of north central rural Victoria in Australia. A pre-condition for inclusion in the study was that the pharmacist had at least weekly contact with at least one patient with intellectual disabilities. Exploratory interviews of varying lengths (20–50 min) Questions asked related to the pharmacists' current perception of their role in the care of patients with ID, barriers to optimal provision of that care and solutions to these barriers	Data from the semi-structured interview was analyzed thematically via a 3 stage coding process; open, axial and selective. Themes were illustrated and collated	The community pharmacists perceived their main role in the care of patients with ID to be in medication management (similar to their principle role in the non-ID population) However the need to spend additional time counselling a patient with ID was acknowledged, as was the important role of the patient's carers in conveying this information. Time resources, education and training and experience in the area of intellectual disabilities were identified as barriers to optimal provision of care, as were inadequate professional. Collaboration and ability to communicate effectively with patients. Solutions identified by the pharmacists included education and training in the field of ID (particularly in the area of communication skills), increasing staffing and increasing interprofessional collaboration in the care of these patients

Table 1 continued

Publication details, country	Study aim(s)	Study design	Study setting and participants	Outcome measures	Findings
Strydom A, Forster M, Wilkie B, Edwards C, Hall I Patient Information Leaflets for people with learning disabilities who take psychiatric medication *British Journal of learning disabilities 2001, 29 22–26* *UK*	To identify information required by people with ID in order to underpin the design of readable patient information leaflets for this population. As a secondary aim, the authors wished to determine where patients currently sourced medication information	Descriptive, qualitative study (use of a semi-structured questionnaire)	Questionnaire administered to 21 people with intellectual disabilities to identify information required to design a readable patient information leaflet and identify gaps in their medication knowledge Participants were selected from three different locations. All were able to communicate verbally and were selected for their range of experience in taking medication (some were not currently taking any medication) The results from the questionnaire were used to inform decision making in drafting the leaflet. The questionnaire was also used to identify patients' current knowledge of prescribed medication. Further consultation then took place before a final leaflet was prepared	Patients experience and perceived difficulties taking medicines Whether participants received assistance in taking their medications Who was participants' information source in relation to their medicines Participants' perceived ability to read labels and standard patient information leaflets Participants' ability to name their medications, list the indication and name side effects associated with the medication Participants' views about the information a suitable patient information leaflet should contain and the format of that information	All individuals interviewed were taking prescribed medication or had recently taken prescribed medication Two-thirds of those interviewed had received help from carers in taking the medication 50 % of participants used doctors as a source of info relating to their medication. Two patients (10 %) used the community pharmacist as a source of information 52 % of those interviewed were unable to read the medication label on their medicine Over 60 % said they could understand very little or none of the associated patient information leaflet Most people knew the name of their prescribed medicines or the approximate name (74 %) 79 % of those knew the indication or approximate indication 38 % could not name any side effects or contraindications associated with their medicine The vast majority of patients (20/21) wanted a readable leaflet, the indication and all side effects being the most frequently cited important desired by patients on these leaflets The community pharmacist was rarely used or viewed as an information source
Clarke DJ, Pickles KJ Lithium treatment for people with learning disabilities, patients' and carers' knowledge of hazards and attitudes to treatment *Journal of Intellectual Disability Research,1994 Vol 38 187–194* UK	To examine patient and carer knowledge of lithium and it's adverse effects among people with intellectual disabilities	Qualitative, exploratory study of patients and carers (use of semi-structured questionnaire)	Questionnaire based study of 25 people with intellectual disabilities (16 with severe learning disabilities, 9 with mild) receiving lithium were identified by psychiatrists and gave consent to partake. Interviews were carried out by researchers in order to rephrase any questions that patients were not able to understand. Questionnaires used were Lithium Knowledge Test (LKT), Attitudes to Lithium Questionnaire (LAQ), Lithium Questionnaire (LK). Of the 25 patients 10 were resident in hospitals, 9 in community residential facilities (CRF) and six lived with family	Carer and patient score on the 1. Lithium knowledge Test 2. Lithium Attitude Questionnaire 3. Lithium Questionnaire	All 25 carers completed the questionnaire, 9 of the patients completed the questionnaire The mean LQ Score for carers was 6.3 (scored out of 12) The mean LQ for patients was 5 The mean score on the LKT was 9.8 for carers (scored out of 22) The mean score on LKT was 7.4 for patients with intellectual disabilities 11 out of 25 carers received written information about lithium; one received this information from a pharmacist. 8 carers were happy with the knowledge they had received. Two patients reported that they had received information, none from a pharmacist The pharmacist was only a source of information relating to lithium for one patient residing in the community

There were two intervention studies [31, 33], three reports of service provision [27–29] and three qualitative studies of pharmacists' and people with IDs' perceptions and views [26, 30, 32].

Pharmacist interventions

Neither of the intervention studies used either random selection of participants nor a control group for comparison; one used a pre- and post-intervention quasi-experimental design [31] and the other a variant of an action-learning approach to identify and address problems [33]. Although both involved community pharmacists their role was to provide medicines and advice about medicines use to the care staff of people with ID in residential homes. In one study physicians were told of pharmacists' recommendations and on one occasion one facility held a multidisciplinary medicines conference in which the pharmacists, psychiatrist and general practitioner participated. Pharmacists review identified actual and potential medication errors and problems and most of their recommendations were accepted and implemented [31, 33]. However, although there was a reduction in the number of problems associated with enteral tube administration [31], an unacceptable number remained and a more fundamental re-design of the service process was prompted by the results of the study. The Danish study was conceived as a feasibility study within the MRC guidelines for evaluating complex interventions [33, 34]; nevertheless the study applied a quality improvement approach and reported numerous and substantial changes to the medication use process in each of the four sites and all the participants valued the intervention and the pharmacists' contribution.

Pharmacist involvement in service provision

Of the reports describing service provision [27–29], two were pharmacy services [27, 28] and one was a psychiatric service [29]. All three involved the pharmacist working in a multi-disciplinary team. One described the contribution of pharmacists to a multidisciplinary service to identify and treat patients at risk of low bone mineral density but it did not include any data comparing previous care [28]. Brahm and Brown reviewed a State-wide service for people with ID and included an analysis of retrospective time-series data showing changes in medicines use [27]. Parkes recorded the views of people with ID who were admitted to a traditional psychiatric service or to an integrated psychiatric service which included a pharmacist and gave an insight into the impact of their work with the participants [29]; the inference in the report was that a pharmacist was not involved in the traditional service. The pharmacists' roles, as described in these reports varied according to the nature of the service being provided and two [28, 29]. Nevertheless, while one was located in a hospital [29], the others provided advice and recommendations to 'intermediate care' facilities [28] and to care facilities and to those caring for people with ID living in the community [27]. Brahm and Brown describe the most comprehensive range of pharmacist activities in which included individual patient care and its documentation but the data demonstrates the level of activity and not patient outcomes [27].

Qualitative studies

All of the qualitative studies used convenience samples, one used semi-structured interviews based on an interview guide developed by the research team [32], one used a questionnaire with semi-structured questions developed specifically for people with ID by the researchers for the study [30], and the other used questionnaires designed for the general population administered by a member of the care team who repeated and re-phrased questions as they considered appropriate [26]. The community pharmacists' interviews were analysed for themes, coded and independently confirmed and data saturation was achieved [32]; the other studies were information gathering exercises [26, 30].

In their study of community pharmacists Di Blasi and colleagues suggested that the brevity of some interviews was a consequence of lack of confidence and experience in consulting with people with ID [32]. The pharmacists saw their role in traditional terms, as providers of information and advice and their concerns and the barriers that they identified were about the difficulties of communicating with people with ID and none referred to the range and complexity of the medicines used or to the clinical needs of the patients. The solutions perceived by pharmacists were directly related to education about communication, the availability of resources and the time required for consultation. However, a minority had engaged with people with ID and had developed a *modus operandi* for interaction and all the pharmacists thought collaboration with carers and other professionals important for this group of patients.

Psychiatrists assessed knowledge and understanding about lithium [26], and psychiatrists and staff of a patient support group for adults with ID explored the sources of medicines information and the information needs of patients and used these in the development of patient information leaflets (PILs) [30]. In both studies, pharmacists were mentioned as a source of medicines information. Of the 25 participants in Clarke and Pickles' study, the mean age was 37 years (range 20–57) and they lived in hospital, community residential care or at home with their families. Eleven carers reported receiving written or verbal information about lithium, one received this information (written) from the pharmacist [26]. Two patients had received information about lithium, none had received this from the pharmacist.

For the study of PILs people were approached in three different locations and they were young (mean age 29 years; range not specified), took a mean of two medicines (range 1–7) but some (number not specified) were not taking any medicines and most (number not specified) did experience problems with their medicines [30]. Although their knowledge of their medicines overall was good, none was able to read the label on their medicines and only 2 of the 21 participants used a pharmacist for information and none knew that community pharmacists could provide them with this information. Most could not understand the information in the PILs and all wanted to know more about the side effects of their medicines.

Discussion

No research into the provision of Pharmaceutical Care for people with ID was carried out between 1994 and 2014. In one study [27] pharmacists provided a wide range of services but pharmaceutical care was not described. In total, only two intervention studies [31, 33], 3 reports of pharmacists contributing to services for people with ID [27–29] and one report of pharmacists' attitudes and opinions about caring for people with ID [32] were published in this 20-year period. Most studies described pharmacists acting as part of an inter-disciplinary team, for patients within an institution or in sheltered accommodation. There were no studies of patients' or carers' views of pharmacists' contribution to care. The majority of studies identified in our review originated in the USA or Britain, suggesting that either this research is of interest only in certain, high income countries, or that research in other countries is published in a non-English language journal not reviewed here for dissemination to a local audience.

The aims and objectives of the studies were very disparate and only 4 of the studies were concerned with pharmacists' roles while in the remaining 4 pharmacists were involved as part of a team or were mentioned by people with ID or their carers. Similarly, the methods used in the studies were all different and the results reported were intermediate outcomes or qualitative findings and provided a limited view of pharmacists' performance. Not surprisingly, the review of medicines and/or administration of medicines emerged as a common theme but brief descriptions of the patterns of medication use, or change in use and of error detection and correction that were presented precluded any detailed comparisons. The authors of the intervention studies considered them to be preliminary and both reported that more detailed and extensive studies would follow [31, 33]. Neither the intervention studies nor the qualitative studies extended beyond single institutions or programmes and served local patient populations. Inadequate staffing and resources have been described in one publication [23] and anecdotally the impression of single pharmacists alone in people with ID or of having responsibility for people with ID as part of a wider scope of practice is consistently obtained, at least in Europe. These factors combined with the study designs employed, the small sample sizes and the lack of robust outcomes mean that it is not possible to draw definitive conclusions about the effectiveness of pharmacists' interventions because there is no substantive body of evidence to evaluate. Nevertheless, evidence of need for medicines information and support in medicine use is apparent from the qualitative studies, from the report of the prevalence of low bone density and taken together with other studies from the intellectual disability literature [35–37], pharmacists' of this population and the development of a research agenda could have a major impact on the lives of people with ID.

Although this review was limited to a 20 year period, a search of the two decades before only found three substantial clinical pharmacy studies set in institutions for people with ID published in 1977 and 1982 [38–40]. All used a retrospective chart review to examine the impact of pharmacist recommendations for hospitalised patients and showed reductions in drug use, particularly for behavioural problems. Only Brahm and Brown's description illustrates the development of these types of services for patients outside hospital in the last 20 years suggesting that little has changed [27]. Despite the increasing numbers of people with ID who have been moving from institutions to the community, no substantial, systematic studies of the role or impact of pharmacists in caring for these patients under these conditions have been reported. Review of mental health pharmacists' impact in institutional and other settings have shown that there are many more studies of patient groups other than people with ID [41, 42] and it is notable that Finley and colleagues also identified the same three studies published prior to 1984 discussed above [42].

These systematic reviews have shown pharmacists' positive impact on medicines use in patients with mental health conditions in institutional and other settings but that it is only since around 1990 that higher quality studies have been conducted limiting the scale of the evidence base [42]. Similar to people with ID, other vulnerable populations have complex needs and are at risk of medication errors [43, 44]. Clinical medication review led by pharmacists or in collaboration with other professionals in older people in primary care, in care homes, with dementia or mental health conditions have demonstrated significant reductions in number of inappropriate medicines, medication errors, omissions and medicines optimisation [45–48].

Such structured medication reviews are accepted as an appropriate part of collaborative care and need to be adapted for the needs of people with ID, assessed and research findings disseminated so that practice can be developed and policy-makers influenced.

Several factors may account for the paucity of research in people with ID; challenges associated with informed consent when carrying out research in this population [25]; Intellectual Disability is recognised to varying degrees as a specialist area of practice in medicine, psychiatry and nursing, whereas in pharmacy the communities of practice are usually broader, such as psychiatric or mental health; lack of education and experience in communicating and providing pharmaceutical care to people with ID; inadequate documentation of and publication of practice experiences; and lack of structured services within primary care for people with ID and of opportunities for collaboration with general practitioners. A need for education of staff and caregivers of people with ID has been previously identified [49].

Strengths and limitations

Thorough and independent searches and assessments of the literature were made and agreement was unanimous. The 20 year period of study inclusion was chosen to reflect the changes in care and service provision for people with ID and the development of pharmaceutical care. No searches were carried out to identify relevant unpublished theses, conference abstracts were not included and studies in languages other than English were not included.

Conclusion

The limited evidence available suggests that pharmacists can make a positive impact on the quality of medication use for people with ID in collaboration with other healthcare professionals and carers. Pharmacists were successful in identifying drug therapy problems and in resolving them, demonstrating that a structured medication review in people with ID has value. However, the literature suggests that these interventions do not take place frequently in this population, or if they do, the interventions are rarely published. Therefore the objectives of the review could be only be answered to a limited extent.

Education and training (particularly in the area of communication skills and the specific morbidities experienced at a greater frequency by people with ID) and the development of validated tools for use in interventions would help pharmacists practice. Dissemination of appropriate medication related information to people with ID and their carers would complement pharmacists' activities and would promote adherence and patient safety. Quality indicators for medicine use for people with ID who have behaviour disorders have been recently developed which support the development of effective collaborative care pathways with other healthcare professionals [50], and extension of indicators to other conditions and to those with ID who are multimorbid would be useful. Pharmacists' organisations need to create awareness among people with ID and among other health care professionals that they have the skills and capacity to become active members of the primary healthcare team in the care of patients with intellectual disabilities and support the development of effective collaborative care pathways with other healthcare professionals.

Further research will be needed to provide robust evidence of the benefits of providing pharmaceutical care to people with intellectual disabilities and to inform future policy.

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