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Pearl Harvesting Autism

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Graduate Program in Education

A thesis submitted in partial fulfillment of the requirements for the degree in Master of Education

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Pearl Harvesting Autism

by

Mariya Gruntovskaya

Graduate Program in Education

A thesis Submitted in Partial Fulfilment

of the Requirements for the Degree of

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The School of Graduate and Postdoctoral Studies

Western University, London, Ontario, Canada

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Abstract

This thesis addresses the difficulties of on-line information searching as it relates to the topic of autism. A review of existing search strategies is presented and their limitations are discussed. A new method for deriving a set of search-terms for comprehensive searching, Pearl Harvesting, was tested here to determine the necessary search terms (i.e., synonym ring) for ERIC and PsycINFO databases. Once discovered and validated, a synonym ring can be copied and pasted directly into the search box of the database, providing a simple, thorough and time saving way of conducting on-line research in the field. This easily used method is applicable for use by professionals across disciplines. Specific characteristics of the ERIC and PsycINFO databases are discussed and conclusions are presented in relation to Pearl Harvesting.

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The prevalence rate of autism spectrum disorders (ASD) has been steadily increasing, and is now at 1 in 68 according to the estimates from the Center for Disease Control and Prevention and Developmental Disabilities Monitoring Network (2015). The social and behavioural deficits associated with this disorder severely limit these children. Consequently there has been much attention in many professional fields to research the causes of this disorder, and provide empirical support for interventions (Amaral, 2006; Finkle, Drager, & Ash, 2010). As the growing demands for evidence-informed decision making require quality research studies to inform practice, there is a need for a thorough and comprehensive information search framework to locate and constantly update research information for this important topic. Existing search strategy protocols are limited, so a recently developed information retrieval framework, Pearl Harvesting (Sandieson, Kirpatrick, Sandieson, & Zimmerman, 2010) was applied and tested here to investigate whether it could be used to create a comprehensive search strategy for locating research information for the area of autism. Such a framework is intended to provide support to researchers and professionals working in the area, so that they can keep abreast of latest developments and historical trends, across various professions. The success of the Pearl Harvesting Information Retrieval Framework (PHIRF) in the retrieval of essential, diagnostic keywords for the topic of Developmental Disabilities

(Sandieson et al., 2010), as well as for giftedness (Sandieson & McIsaac, 2013), suggested that this method would also prove successful for the topic of autism.

The Importance of Effective Searching in the Area of Autism

There are two related reasons for establishing an effective search strategy that is comprehensive and precise for searching the literature in the field of autism. One pertains to inclusive educational practices. The other is the evidence-informed movement in educational practices.

With the passing of the Education Amendment Act in 1980 in Ontario, and other similar mandates throughout North America, public education has been directed to a more inclusive institution of learning for all types of students (Bennett & Gallagher, 2012; Moores-Abdool, 2010). Associated with the increase of autism diagnosis and identification (a 500% increase in the past 10 years; Moores-Abdool, 2010), is a significant number of students with autism within inclusive school settings. Teachers are unprepared, not confident in their abilities, and have a need for information on all aspects of special education; yet they lack the knowledge and resources for finding evidence-informed research (Bennett & Gallagher, 2012; Moores-Abdool, 2010; Servais, 2012). The realization of inclusive practices is met with skepticism from educators (Bennett & Gallagher), so offering a way for teachers and educators to be able to easily access specific research information on autism may make for more knowledgeable, confident, and effective educators.

Evidence-informed policy and practice has also necessitated comprehensive literature search strategies. In the United States, the No Child Left Behind act, mandated that teachers use

instructional practices based on evidence-informed (i.e., scientific) research. Since the law was passed in 2001, schools are expected to be aware of and to apply evidence-informed practices in their educational programs (Eisenhart & Towne, 2003). The value of evidence-informed practices is that the educational programs will have been proven to be effective (Eisenhart & Towne; Reichow, & Volkmar, 2011).

The concept of evidence-informed practice is multi-faceted, involving the following: The best current evidence, clinical expertise, and client choice (Reichow & Volkmar, 2011). As in other professional fields, the movement towards evidence informed practice requires a comprehensive search of the literature and an appraisal of the available data in order for new and accurate findings to be effectively applied to educational settings (Reichow, 2011). Interested educators and researchers therefore, need to have the strategies to accurately search for existing, empirically supported interventions. Failure to locate pertinent literature could result in decisions that do not effectively serve the well-being of those with autism.

Current Issues in Information Searching

The shift to on-line database research publication has created a vista to vast quantities of information. The new and expanding on-line research sources have potential for providing easily accessible and readily available data. Research studies from across the globe and across wide time frames are there for the information searcher to gather, appraise, and base decisions upon. However, the search strategies currently used to access this information were developed at the inception of digital databases, have changed little, and were not meant for the volumes of information that have been produced (Borgman, 2007). As evidenced from a number of studies, there is a lack of effective comprehensive search strategies used by information seekers in academic and professional disciplines (Herzberg & Rudner, 1999; Sandieson et al., 2010).

The following subsections will discuss issues that relate to difficulties in on-line data base searching, database indexing and current search strategies.

Current Search Strategies

Subject searching/database indexing. Subject searching involves the use of the database thesaurus or the controlled vocabulary on a topic provided by a specific database. Inconsistencies sometimes arise between databases in their inclusion of vocabulary. In some cases the lists may not be complete and/or vary from one database to another (Ardent, 2007; Sandieson, 2010). When *autism* is entered in the search terms of the PsycINFO thesaurus, the terms, *autism*, *autism spectrum disorders* and *early infantile autism*, are provided. When the same search is made in the ERIC database, only the terms, *autism* and *autism spectrum disorders* are provided.

Free text searching. In this case the researcher decides what terms to use. It is “up to the researcher to think up of all the possible terms that different authors would have used for a particular idea” (Arendt, 2007, p.4; Sandieson et al., 2010). This strategy becomes problematic when dealing with the topic of autism due to the non-uniform way that the disorder has been categorized and the way it is described.

Manual searching and document searching. This search technique is carried out by first choosing key journals and then manually searching through the bibliographical information provided for relevant articles. Not only is this time consuming there is also the issue of a lack of a definition for what a *key journal* is (Sandieson et al., 2010). Because there is no definition for what a key journal is, researchers may be looking through different journals as per their prior knowledge or exposure and may miss relevant articles that may be found elsewhere.

Citation Tracking. This strategy involves using a specific article as a source for finding other articles that relate to a topic of interest. One may find studies that have been cited by an article of interest, known as *forward tracking*, or use references used in a study as sources, *backward tracking* (Sandieson et al., 2010). The limitation with this strategy is that there may be a disconnect between disciplines or theoretical inclinations of individuals allowing for only specific areas of thought to be connected. In this way, articles or authors that are from another discipline or field may not be found using this strategy.

Searching the Literature for Information on Autism

ASD exhibits itself as a spectrum of disorders and specifically by impairments in three core areas of functioning: communication, stereotypical/repetitive behaviours/interests and a difficulty with recognizing and interpreting social cues in interaction; thereby debilitating the ability to form successful social relationships (Reed, Hirst, & Hyman). In DSM 5, autism spectrum disorder is used as an umbrella term and diagnosis that replaces previous subtypes of the disorder: E.g. autistic disorder, Asperger's disorder, childhood disintegrative disorder, and pervasive developmental disorder—not otherwise specified (PDD-NOS) (Vivanti, et. al. 2013). A growing body of research and funding in the field has led to an exponential growth of information that is being released by researchers in various disciplines and professional fields (Reichow & Volkmar, 2011).

Since the 1940's when autism spectrum disorder-like symptoms were first identified, this *heterogeneous neurodevelopmental disorder* (Pasco, 2010) has undergone a rapid evolution in relation to what defines it, the criteria for diagnosis, and the terminology that is used to describe it (Cashin, 2006; Pasco, 2010; Phettrasuwan, et al., 2009). The ongoing and rising interest in ASD publicly, politically, and professionally world-wide provides for a continuum of research

and thereby for an on-going exploration and evolution of the disorder (Pasco; Reichow, & Volkmar, 2011). As a result, key terms used for performing research tend to change over time and are not uniform across disciplines and countries. To illustrate: Since the initial discovery of autism-like symptoms in the 1940's, the following terminology (amongst others) has been used to describe the disorder: *Classic autism*, *Kannerian autism*, *infantile autism*, *pervasive developmental disorder-residual type*, *childhood schizophrenia*, and *autism psychoses*. (Petrasuwan, et al., 2009). Autism, being a spectrum disorder, can be described in many ways and there are no specific, standard set of terms that are universally used by all professionals who deal with the disorder (Bennett, 1996). In fact, due to the diverse continuum of autism, there is even documented professional confusion around terms used to describe autistic-like symptoms (Bennett, 1996; Pasco, 2010).

Difficulties in conducting research on autism exist for all individuals involved with research on the subject: Academic researchers, educators, health care professionals and parents of children on the spectrum (Cashin, 2006). Because of the interchangeability of terms used in literature, the lack of cross-professional standards, and the incremental amount of information available, researchers of all levels of expertise are faced with an overwhelming task of finding the material(s) they are looking for using the available search strategies (Arendt, 2007; Herzberg, & Rudner, 1999; Wessell, Tannery, & Epstein, 2006). Research in autism is carried out with many disciplines with diverse theoretical backgrounds and research methods. It is important that researchers consider, acquire, and synthesize research across disciplines (Reichow & Volkmar, 2011). Bennett (1996) conducted a study to determine how therapists, paediatricians, educational psychologists and specialized teachers described autism. The terms used were: *autistic*, *autistic features*, *autistic syndrome*, *pervasive developmental disorder*, *severe communication disorder*

and *Asperger*. The results showed a disparity between the terms used. For example, the most common term to describe autism by paediatricians was *autistic features*; for the educational psychologists the most common term was *severe communication difficulties*.

Another discrepancy in the field of autism research can be illustrated by a survey conducted by Heidgerken, Geffken, Modi, and Frakey (2005). The researchers compared DSM-IV and general knowledge criteria of autism and found that primary health providers (e.g., professionals and residents in training in the fields of neurology, paediatrics, child psychiatry, clinical psychology, speech pathology and family practice) did not hold currently research-based beliefs on autism. This is alarming as more often than not, the above listed professionals are the first to come in contact with the children who would benefit from an early and accurate diagnosis (Heidgerken et al., 2005).

There is then a need for a way of overcoming these problems in locating information on autism and for finding a way to address the inconsistency in terminology involving the disciplines that deal with autism. The intention of this thesis was to create a comprehensive set of terms on the topic of autism that allows for an effective searching of the abundant literature across professional fields for a more uniform and clear perspective on the disorder. To this end, the Pearl Harvesting Information Retrieval Framework was used.

Method

The process for carrying out the research necessary to complete this thesis was based on the Pearl Harvesting Information Retrieval Framework proposed by Sandieson (2006), Sandieson et al. (2010), and Sandieson and McIsaac (2013). The assumptions behind this search strategy are that in existing literature, there are a number of articles on a topic and that within

these articles one can find terminology to use as “identifying search keywords” (Sandieson et al., 2010, pg.163). In essence, this approach differs from traditional search methods in that its focus on terminology brings it closer to the content of the information rather than prescribing a general set of search strategies to uncover relevant work. The search terms are found through an initial bibliographical content analysis of the articles: The articles are the pearls. The full set of terms acquired, which represent a topic, comprise a synonym ring. The synonym ring allows for comprehensive searches in that the range of terms accounts for all expressions of the topic used by both researchers and indexers; this maximizes total recall of articles on a topic. It also allows for precise searching in that all individual terms are verified for their ability to locate topic relevant citations. This method was applied and tested with the topic of autism for the purposes of creating a comprehensive pearl-harvested synonym ring that could be used across disciplines interested in conducting research on the topic. The steps are listed below.

Pearl Harvesting Framework Applied to Autism

Step 1. Choosing a representative sample of articles.

In order to gather a sample of articles that represented the range of terminology used in the autism field of study, a broad range of articles from across disciplines was located. An initial search was conducted in the PsycINFO and ERIC databases using a list that included autism and systematic review terms (E.g., *autis** AND “*research synthesis*” OR *meta-analysis* OR “*meta analysis*” OR “*systematic review*”). The two databases were employed as they are commonly used amongst researchers and are specific to education and psychology. Another study is ongoing investigating the use of autism terminology in the medical database MEDLINE (Sandieson & Torabi, in preparation), so that database was not used here. Systematic reviews were used as they provide a ready source of peer reviewed journal articles compiled around specific topics.

All of the bibliographical information (title, abstract, descriptors, identifiers) from the retrieved articles, a sample of 210, from the initial search was reviewed. These articles were organized according to specific research study areas: 1. social/communication, 2. education, 3. attachment, and 4. behavioral/developmental. This provided a sample of articles representative of a variety of disciplines. A pilot search of PsycINFO and ERIC provided the confirmation for the above categories. Creating a data-base of autism terms as they pertain to different professional fields provided a sampling of terms across disciplines. The initial search produced 578 articles. The first 200 articles were analyzed based on their bibliographic information and 126 were found relevant. The inclusion criteria for autism relevance was that the characteristics for autism as specified by the DSM IV or 5 had to be met. If an article merely mentioned autistic-like symptoms it was not included. Relevant articles were categorized according to the related discipline and terminology pertaining to autism was recorded from each one.

Step 2. Extracting the relevant search keywords.

Possible terminology used to describe autism was established by analyzing the bibliographical descriptor, title and abstract information of each article. All potentially relevant terms were recorded and coded according to what field of study the articles were completed in.

Step 3. Refining the list of search keywords.

To refine the list of key words pooled in step 2, the terms that have the same root word were shortened with the truncation function (*). The truncation function allows for all words with the same root to be retrieved during a search. For example *autis** = autism, autistic.

In this step, the keywords retrieved in step 2 were refined and tested to determine those that are essential terms. Essential terms are those that retrieve specific articles that could not be found

using any other terms. This was tested through a Boolean subtraction procedure where each term is separately and sequentially placed in the first search box and the rest of the terms in the second search box; joined by the NOT command. This removes all citations found by the synonym ring except for the ones unique to the first term used (Sandieson & McIsaac, 2013). Also, keywords retrieved were analyzed according to their recall (number of articles) as well precision (relevancy to the area of autism). Relevancy was assessed by noting whether a citation pertains to the characteristics of autism as defined by the DSM-IV. Precision and relevancy was also determined based on an article/study's inclusion of the topic of autism, Fragile X, or Asperger syndrome. Any article with relevance was coded as having precision.

Inclusion/exclusion relevance criteria. Articles that did not include a mention of autism, Asperger's, or Fragile X directly were deemed not relevant; as well as the articles that mentioned the terms but, as either exclusion criteria or in passing in the introduction or discussion sections of the paper. Articles that were accepted as relevant included one or more of the above mentioned terms directly. The article was accepted if the topic of autism was discussed as a focus or as a part of a broader study. For example, in the article, "A social-ecological analysis of the self-determination literature" (Shogren, 2013) autism is included under the broader subject of students with different disability characteristics as recognized by the Individuals with Disabilities Education Act in relation to self-determination characteristics. This article was included because the study did relate to individuals with autism.

In most cases it was clear from the existing bibliographic information as to whether the articles contained or did not contain reference to the inclusion criteria of autism. However, in some cases it was not. In these cases a further bibliographic field not used in the default *anywhere* command search of the Proquest databases was further used to determine whether the

full text of the article should be reviewed for a definitive answer. Each citation found in an *anywhere* search has a corresponding list of its reference included in a data field. The exact number of references for an article is given and by clicking on the *reference* button the list of an article's references can be viewed. In this case, by reviewing the list of references, a further content analysis was done to see if any of these references contained terms that matched the inclusion criteria. If they did, this was taken as an indicator that the original article was worth further pursuing in its full text version to see in a more definitive way whether it contained a reference to autism.

Step 4. Validating the search keywords in the synonym ring.

The terms found in step 3 of this research were validated to ensure that the Pearl Harvesting synonym ring had included all relevant terms. To do this, the synonym ring produced was compared with the search terms used by existing systematic reviews on autism. Ten systematic reviews were chosen, based on recency, and their search terms were reviewed to see if they used different terms. Also, to achieve validation for the created list, the synonym ring was used to see how many citations were found with it, compared to the terms most frequently used in the systematic reviews and to the combination of all terms used in the systematic reviews.

Results

Step 1: Choosing a Representative Sample of Articles

The representative sample of articles and relevant keywords were chosen according to categories based on diagnostic terms (e.g., autism, pervasive developmental disorders) and symptomatic terms (e.g., communication disorders, behavioural disorders). This was done as

there was a prior indication that symptomatic terms may not have been necessary in the search process (Sandieson, 2013). The terms were edited with the use of the truncation symbol (*).

To start the research process, a sample of representative articles was produced. The sample was gathered by simultaneously searching ERIC and PsycINFO databases for meta-analyses or systematic reviews. The keywords used to complete the search were: *Autis** (on first line) “*research synthesis*” *OR meta-analysis OR “meta-analysis” OR “systematic review”* (on the second line, joining the two with the AND command). Only peer reviewed articles were included. The articles produced were sorted according to relevance.

The search produced 578 citations. All of the studies retrieved were either meta-analyses, research syntheses, systematic review or meta regression analyses. A sample of 210 articles were reviewed based on the bibliographical information and then a final set of 128 relevant articles were selected, which dealt with autism. The 82 non-relevant articles did not mention autism, but predominantly dealt with ADHD. A content analysis was done on the articles within the four categories (e.g., social/communication, behavior(al)/development(al), research/alternative treatments and medical/genetic) looking for potential search terms relevant to autism.

Step 2: Extracting the Relevant Search Keywords

The 128 relevant sample articles were analysed to determine if there were any potential search keywords related to autism based on their bibliographical information. All potentially relevant terms were recorded and sorted according to one of the four subject categories.

Step 3: Refining the List of Search Keywords

The list of terms produced was sorted into two categories; *potential diagnostic terms* and *potential symptomatic terms*. The list was also refined using the truncation symbol (*). For example: *Disability, disabilities*, now refined to *disab**.

Summary of potential diagnostic terms. The potential diagnostic terms were: *Asperger**, *pervasive developmental disorder**, *pervasive developmental delay*, *autis**, *ASD**, *developmental disab**, *AS*, *ASP*, *PDD-NOS*, *PDD NOS*, *AD*, *PDD*, *HFA*.

Summary of potential symptomatic terms. The potential symptomatic terms were: *Behavior problem**, *intellectual disab**, *psychiatric disorder**, *emotional disturbance**, *Psychiatric symptom**, *pervasive develop**, *mental disorder**, *developmental disorder**, *developmental-behavioural disorder**, *developmental-behavioural problem**, *developmental-behavioural disab**, *psychopathology*, *mental* retard**, *developmental delay**, *Rett syndrome*, (*Rett**), *neurodevelopmental disorder**, *schizophrenia*, *disruptive behavior disorder**, *non-psychotic disorder**, *nervous and mental pathology*, *severe communication disorder**.

Table 1

Results from Steps 1, 2, and 3.

Category	# of Citations	Directly Related Autism Terms (potential diagnostic terms)	Symptomatic Terms (potential symptomatic terms)
Social/communication/ interpersonal competence/ anxiety/social cognition	27	Asperger*, pervasive developmental	

			disorder*, autis*, ASD*, developmental disab*, High- functioning autism (HFA)
Behavior(al)/development(al)/ Treatments/interventions	18	AS	Behavior problem*, intellectual disab*, psychiatric disorder*, emotional disturbance*
Research/other (alternative therapies, screening, novel treatments, comorbidity...)	35	ASP, PDD- NOS, AD	Psychiatric symptom*, pervasive develop*, mental disorder*, developmental disorder*, developmental- behavioural disorder*, developmental- behavioural problem*, developmental- behavioural disab*, psychopathology, mental retard*, developmental delay*
Medical/Genetics/MRI/DTI/ Pharmaceuticals/neurology/heritability	48	PDD	Rett syndrome, (Rett*), neurodevelopmental disorder*, schizophrenia, disruptive behavior disorder*, non- psychotic disorder*, neurological illness

Determining diagnostic essential terms. The potential terms were tested for uniqueness and relevance to determine if they were essential to the synonym ring. Uniqueness was tested using a Boolean subtraction procedure. An individual term was entered into the first search box and the rest of the potential terms were entered into the second search box on the line below joined by the NOT command. This procedure was completed within ERIC and PsycINFO databases individually.

Relevance was tested by determining if the unique citations retrieved articles that directly pertained to autism. Citations that either directly related to autism or mentioned autism/Asperger's were marked as relevant. A citation was deemed non-relevant if the article did not relate to autism in any way or if autism was included as a part of an exclusion criteria within the study with no further mention. For example, if the article used the phrase autism-like symptoms but did not directly refer to autism beyond that it was not deemed relevant.

Potential symptomatic essential terms were tested separately. Each term was tested against all of the terms in the diagnostic term list by entering the term, e.g., "behavior problem*" followed by the NOT command, then, all of the diagnostic terms.

Final analysis of diagnostic and symptomatic terms in ERIC. An initial testing of potential diagnostic terms determined that the following terms should be excluded from further research (terms that produced no relevant or unique citations) were: "Pervasive developmental delay", "PDD NOS", PDD-NOS, PDD, HFA, AD. The term, "Fragile X" was added to the final list of potentially diagnostic terms due to its physiological relationship to autism, noted as being

a genetic cause of autism (Belmonte & Bourgeron, 2006). The search terms that were used for the final analyses were: Autis* OR asperger* OR "pervasive developmental disorder*" OR "developmental* disab*" OR ASD* OR ASP OR AS OR AD OR “Fragile X”.

The same Boolean procedure was used to test each potential diagnostic term as mentioned above. For example; to test the term “autis*”, autis* was entered in the first search box, and the terms asperger* OR "pervasive developmental disorder*" OR "developmental* disab*" OR ASD* OR ASP OR AS OR AD OR “Fragile X”, in the second line below, connected with the NOT command.

Relevance and the number of relevant (i.e., precision) was determined by analyzing the unique citations. Since there were a large number of unique citations found, only a sample of these was reviewed. The size of the sample was found by using an online sample size calculator retrieved from: <http://www.raosoft.com/samplesize.html>

Table 2

Final Analysis of Diagnostic Terms for Autism in ERIC

Term	# of Citations	Calculated sample size	# of Unique and Relevant Citations
“developmental* disab*”	3233	366	39
Autis*	2699	337	318
Asperger*	138	102	101
“Pervasive Developmental disorder*”	40	37	18
ASD*	19	19	1
ASP	3173	343	5
AS	271 457	384	4
“Fragile X”	52	46	45

The essential diagnostic keywords as determined by this research for searching ERIC were: *Autis**, *Asperger**, “*pervasive developmental disorder**”, “*pervasive developmental delay**”, “*developmental* disab**”, *ASD**, *ASP*, *PDD*, “*Fragile X*”.

Table 3

Final Analyses of the Symptomatic Terms in ERIC

Term	# of Citations Produced	Calculated Sample Size	# of Unique and Relevant Citations
Behavior problem*	5928	361	7
Intellectual disab*	625	239	22
Psychiatric disorder*	287	165	5
Emotional disturbance*	2771	338	15
Psychiatric symptom*	104	83	1
Pervasive develop*	1	1	1
Mental disorder*	2169	327	8
Developmental disorder*	27	26	3
Developmental-behavioral disorder*	0	0	0
Developmental- behavioral problem*	1	1	0
Developmental-behavioral disab*	0	0	0
Psychopathology	1450	304	3
Mental* retard*	5758	361	27
Developmental delay*	452	208	14
Rett syndrome	6	6	0
Rett*	56	49	0
neurodevelopmental disorder*	18	18	0
Schizophrenia	457	209	3
disruptive behavior disorder*	74	63	2
non-psychotic disorder*	0	0	0
nervous and mental pathology	0	0	0
severe communication disorder*	7	7	0

The same inclusion criteria was used with symptomatic terms as with diagnostic terms. Terms that did not produce any unique and relevant articles were discarded. The spelling of “behavior*” only produced relevant citations if typed using American spelling; the British spelling “behaviour” produced no results.

ERIC synonym ring. The final synonym ring for ERIC was: “*Developmental* disab**”, *autis**, *Asperger**, “*pervasive developmental disorder**”, *ASD**, *ASP*, *AS*, “*Fragile X*”, “*behavior problem**”, “*intellectual disab**”, “*psychiatric disorder**”, “*emotional disturbance**”, “*psychiatric symptom**”, *pervasive develop**” “*mental disorder**”, “*developmental disorder**”, *psychopathology*, “*mental* retard**”, “*developmental delay**”, *Schizophrenia*, *disruptive behavior disorder**.

Final analysis of diagnostic and symptomatic terms in PsycINFO. Initial testing of potential diagnostic terms in PsycINFO determined that the following terms should not be excluded from further searches (those that produced NO relevant or unique citations): *AS*, “*PDD NOS*”, *PD-NOS*, *AD*, *HFA*.

Search terms used for final analysis were: “*Developmental* disab**”, *autis**, *Asperger**, “*pervasive developmental disorder**”, *ASD**, *ASP*, *PDD*, “*pervasive developmental delay*”, “*Fragile X*”.

Sample size calculations for the final testing of each term was determined using an online sample size calculator retrieved from: <http://www.raosoft.com/samplesize.html>

Table 4

Final Analysis of Diagnostic Terms for Autism in PsycINFO

Term	# of Citations	Calculated Sample Size	# of Relevant Articles
“developmental* disab*”	15 455	375	9
Autis*	22 443	378	217
Asperger*	227	143	131
“Pervasive Developmental disorder*”	276	161	99
ASD*	456	209	8
ASP	590	233	0
PDD	374	190	1
“pervasive developmental delay”	2	2	0
“Fragile X”	756	255	249

Diagnostic keywords as determined by this research for searching PsycINFO: “*Developmental* disab**”, *autis**, *Asperger**, “*pervasive developmental disorder**”, *ASD**, *PDD*, “*Fragile X*”.

Table 5

Final Analyses of the Symptomatic Terms in PsycINFO

Terms	# of Citations Produced	Sample Size Calculation	# of Relevant and Unique Sources
Behavior problem*	20976	378	17
Intellectual disab*	5628	360	48
Psychiatric disorder*	21320	378	15
Emotional disturbance*	6375	363	6
Psychiatric symptom*	14642	375	0
Pervasive develop*	19	19	9
Mental disorder*	72038	383	5
Developmental disorder*	869	267	20

Developmental-behavioral disorder*	4	4	0
Developmental- behavioral problem*	7	7	1
Developmental-behavioral disab*	2	2	0
Psychopathology	39100	381	8
Mental retard*	15849	376	31
Developmental delay*	1362	300	16
Rett*	835	264	16
neurodevelopmental disorder*	1128	287	24
Schizophrenia	87400	383	5
disruptive behavior disorder*	821	262	11
non-psychotic disorder*	100	80	2
nervous and mental pathology	2	2	0
severe communication disorder*	16	16	0

Inclusion criteria remained uniform throughout the study.

PsycINFO synonym ring. The final synonym ring for PsycINFO was: “*Developmental* disab**”, *autis**, *Asperger**, “*pervasive developmental disorder**”, *ASD**, *PDD*, “*Fragile X*”, “*behavior problem**”, “*intellectual disab**”, “*psychiatric disorder**”, “*emotional disturbance**”, “*pervasive develop**”, “*mental disorder**”, “*developmental disorder**”, “*developmental-behavioral problem**”, *psychopathology*, “*mental retard**”, “*developmental delay**”, “*Rett syndrome*”, *Rett**, “*neurodevelopmental disorder**”, *schizophrenia*, “*disruptive behavior disorder**”, “*non-psychotic disorder**”

Step 4. Validating the search keywords in the synonym ring.

To ensure that the Pearl Harvesting synonym ring had included all relevant terms, the synonym ring produced in this study was compared with the search terms used by existing systematic reviews on autism.

PsycINFO and ERIC databases were searched simultaneously using the term *autis** AND "*research synthesis*" OR *meta-analysis* OR "*meta analysis*" OR "*meta-analytic*" OR "*systematic review*" OR "*realist synthesis*" OR "*integrative review*" OR "*quantitative review*" OR "*quantitative synthesis*" OR "*qualitative review*" OR "*qualitative synthesis*" OR "*critical review*" OR "*literature review**" OR "*review of the literature*" OR "*selective review*" OR "*evidence-based review*" OR *meta-synthesis* OR *meta-ethnograph** OR "*narrative review*" OR "*narrative synthesis*" OR "*umbrella review*" OR "*rapid review*" OR "*scoping review*" (synonym ring for systematic review which had become available during the latter time of the present study, Sandieson, 2014). For the purposes of this analysis, the search with *autis** only allowed for direct retrieval without having to search through actual content of the systematic reviews.

The search brought up 3,614 peer reviewed articles (organized by most recent). The ten most recent relevant studies were analyzed according to their search strategies and the terminology used was recorded. (Table 6). Articles were deemed relevant if they were directly related to research in autism and included a concise ‘research methods’ section describing the key-terms used.

Table 6

Ten Most Recent Systematic Reviews With Search Terms

Name of Study	Author(s)	Date	Type of study	Search terms used
Are opioid antagonists effective in reducing self-injury in adults with intellectual disability? A systematic review.	Roy, A., Roy, M., Deb, S., Unwin, G.	2015	Systematic review	Autis*, <i>autis*</i> spectrum disorder*, <i>autis*</i> spectrum condition*, Asperger*,

				infant* autis*, child* autis*, pervasive* development* disorder*, autis* psychopath*, AS*, PDD, Kanner* Syndrome, atypical* autis*
Anthropometric measurements and nutritional assessment in autism spectrum disorders: A systematic review.	Mari-Bauset,S., Saspe, I., Mari-Sanchis, A., Llopis-Gonzales, A., Suarez-Varela,M.M.	2015	Systematic review	“autism spectrum disorder”, “autistic disorder”
Cognitive behaviour therapy for adults with autism spectrum disorders and psychiatric co-morbidity: A review.	Spain, D., Sin, J., Chalder, T., Murphy, D., Happe, F.	2015	Review	Autis*, autis*spectrum disorder*, Asperger*, development* disorder*
Meta-analysis of receptive and expressive language skills in autism spectrum disorder.	Kwok, E.Y.L., Brown, H.M., Smyth, R.E., Cardy, J.O.	2015	Meta- analysis	Autis*, Asperger*
Transition services for youth with autism: A systematic review.	Westbrook,J.D. Fong, C.J., Nye, C., Williams, A., Wendt, O.,et.al	2015	Systematic review	Autis*, childhood disintegrative disorder*, pervasive developmental disorder*, spectrum disorder*, ASD, Asperger*, Rett*
Technology-aided	Odom, S.L.,	2014	Literature	Autism,

interventions and instruction for adolescents with autism spectrum disorder.	Thompson, J.L., Hedges, S., Boyd, B.A., Dykstra, J.R., et al.		review	Asperger
ASD academic transitions: Trends in parental perspective.	Lee, C., McCoy, K.M., Zucker, S.H., Mathur, S.R.	2014	Qualitative meta-study	Autism, Asperger syndrome
Visuo- spatial performance in autism: A meta- analysis	Muth, A., Honekopp, J., Falter, C.M.	2014	Meta-analysis	Autism, ASD
Autism and lack of D3 vitamin: A systematic review	Pioggia, G., Tonacci, A., Tartarisco, G., Billeci, L., Muratori, F., et al.	2014	Systematic review	Autism, autism spectrum disorder, ASD
What are the ages of persons studied in autism research: A 20 year review	Jang, J., Matson, J.L., Adams, H.L., Konst, M.J., Cervantes, .E., et al	2014	Review	Autism

There was an inconsistency found in the terminology used in the systematic reviews. This variance in search strategies may point to a lack in thoroughness in regards to the research, at least with respect to using online searching. Newly found terms were tested for relevancy and retrieval: “*Infant* autis**”, “*child autis**”, “*autis* psychopath**”, “*kanner* syndrome*”, “*atypical autis**”, “*childhood disintegrative disorder**”, “*autis* spectrum condition**”, and ASC. Though ASC was not found as a search term in the systematic reviews, the term did come up as an abbreviation in the article that was retrieved while testing the term “*autis* spectrum condition**”.

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The new terms found were tested individually for relevancy in PsycINFO and ERIC databases. Each term was tested against the established synonym ring for each database (e.g. “*infant*
autis**” NOT synonym ring as produced by this research for PsycINFO).

Table 7

Testing New Terms in ERIC

Terms	# of Citations Produced	Sample Size Calculation	# of Relevant and Unique Sources
Infant* autis*	0		
Child autis*	0		
Autis* Psychopath*	0		
Kanner* Syndrome	0		
Atypical Autis*	0		
Childhood disintegrative disorder*	1	1	1
Autis* spectrum condition*	0		
ASC	20	20	0

Testing of newly found terms in ERIC produced one unique and relevant citation for the term *childhood disintegrative disorder**. The synonym ring without the new terms was tested against the synonym ring with the new terms added. The synonym ring with the new-found terms produced 1 more peer review article.

Table 8

Testing New Terms in PsycINFO

Terms	# of Citations Produced	Sample Size Calculation	# of Relevant and Unique Sources
Infant* autis*	0		
Child autis*	0		
Autis* Psychopath*	0		
Kanner* Syndrome	0		
Atypical Autis*	0		
Childhood disintegrative disorder*	4	4	3
Autis* spectrum condition*	1	1	1
ASC	533	224	0

Testing of newly found terms in PsycINFO produced unique and relevant citations for the terms *childhood disintegrative disorder** and *autis* spectrum condition**. The synonym ring without the new terms was tested against the synonym ring with the new terms added. The synonym ring with the new-found terms produced 4 more peer reviewed articles.

Conclusion

The intention of this study was to create a comprehensive search tool for researching autism. The Pearl Harvesting framework (Sandieson et al; 2006; 2010; 2013) was investigated to see if it could be used as a guideline to generate a thorough set of search terms which would facilitate a more complete literature search in the area of autism.

The procedures outlined by PHIRF were used to generate a set of terms for locating information on autism in the ERIC and PsycINFO databases (See Appendix). The resulting search term list, compared to the terms used in a list of recent systematic reviews produced a more comprehensive and larger pool of citations. This is not to say that those systematic reviews lacked rigour in general: We do not know this. The authors used other available search strategies to locate their sources such as citation tracking and browsing. However, the larger set of terms found through PHIRF is a resource that those looking for information on autism could readily and effectively use instead of, or alongside, other existing search strategies.

Some features in the present study went beyond the prescriptions suggested by Sandieson and colleagues (2006; 2010; 2013). First, Sandieson suggests surveying the literature across a wide range to collect search terms; however, how this is to be done is not articulated. Due to the vast amount of research that is available in the field of autism, and the cross-disciplinary interest in the field, a unique method was used here to effectively survey the literature and collect the most possible search terms. This was accomplished through specifically surveying systematic reviews that addressed a variety of issues across disciplines. This allowed for a systematic retrieval and organization of possible terminology as may be used universally by those conducting research in autism. The terminology found was therefore inclusive of a broad range

of disciplines related to the field: This ensured that the final product (synonym ring) was as thorough as possible.

Another area where the present study advanced knowledge in locating search terms was with the use of the Reference field in the bibliographic information. It was found, when testing the symptomatic terms for either ERIC or PsycINFO databases that the ANYWHERE (ALL) default command only searches the title, abstract and key word sections of the citations produced. Originally, according to the Pearl Harvesting information retrieval framework (Sandieson et al, 2006, 2010, 2013), bibliographic information was where the relevance of a citation was determined. However, the present investigation showed that on many occasions the articles that produced no relevance when searched for using only the bibliographic information, were relevant if a further search through the Reference section was done. This was predominantly the trend for symptomatic terms.

Based on the limitations of the ANYWHERE command, all symptomatic terms were tested in the following way: If the initial citation did not produce relevant results, the references would be checked. If the references did not include terminology from the diagnostic term list, the descriptor was coded as non-relevant. However, if within the references, a diagnostic term was found, then the full article was accessed and analysed for relevance. For example: When testing the descriptor term *developmental-behavioral problem** using the NOT all diagnostic terms filter, in PsycINFO, one of the citations produced is an article titled 'Detecting children with developmental-behavioral problems: The value of collaborating with parents' (Glascoe, Page, Marks, Kevin, 2011). A search of the abstract and index produces no relevance according to inclusion criteria. Within references, one article with the term *autism* is present. Going further into the full text, the term *autism* is found twice and is mentioned in direct relation to findings

discussed by the study. Similar results were found in ERIC. Thus, according to this analysis, it is important to include both diagnostic and symptomatic search terms for full results, including the Reference field to provide for enhanced searching capabilities. This search strategy is, as of now, related to only ERIC and PsycINFO (i.e., Proquest) databases.

Through the retrieval framework it was also found that the synonym rings for ERIC and PsycINFO are different, with PsycINFO having more symptomatic and diagnostic terms than ERIC. Therefore, when searching either database, it is important to use the appropriate synonym ring in order to ensure that the results produced are both relevant and thorough.

To conclude; the guidelines of the Pearl Harvesting information retrieval method assisted the production of synonym rings that are more effective than the ones being currently used in systematic reviews. The created search term lists make it easier for professionals to conduct research in the field of autism, avoiding the difficulties associated with subject searching, manual, document, and other search strategies. The lists are transparent, enabling anyone wishing to use them to find information on autism by copy and pasting them in ERIC or PsycINFO. This tool is there to enable people to search without having to reinvent the search terms every time through time-consuming and not always effective methods. This has the potential to result in a higher quality of searching for researchers, students, and policy makers in the field.

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Appendix

Synonym Ring for Searching in ERIC

“developmental* disab*” OR autis* OR Asperger* OR “pervasive developmental disorder*” OR ASD* OR ASP OR AS OR “Fragile X” OR “behavior problem*” OR “intellectual disab*” OR “psychiatric disorder*” OR “emotional disturbance*” OR “psychiatric symptom*” OR “mental disorder*” OR “developmental disorder*” OR psychopathology OR “mental retard*” OR “developmental delay*” OR “childhood disintegrative disorder*”

Synonym Ring for Searching in PsycINFO

“developmental* disab” OR autis* OR Asperger* OR “pervasive developmental disorder*” OR ASD* OR PDD OR “Fragile X” OR “behavior problem*” OR “intellectual disab*” OR “psychiatric disorder*” OR “emotional disturbance*” OR “pervasive develop*” OR “mental disorder*” OR “developmental disorder*” OR “developmental-behavioral problem*” OR psychopathology OR “mental retard*” OR “developmental delay*” OR “Rett syndrome” OR Rett* OR “neurodevelopmental disorder*” OR schizophrenia OR “disruptive behavior disorder*” OR “non-psychotic disorder*” OR “childhood disintegrative disorder*” OR “autis* spectrum condition*”

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