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Characteristics of nursing studies in diabetes research published over three decades in Sweden, Norway, Denmark and Iceland: a narrative review of the literature

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Similarities and differences across borders of Nordic countries constitute a suitable context for investigating and discussing factors related to the development of diabetes nursing research over the last three decades. The present study reviewed the entire body of contemporary diabetes nursing research literature originating in four Nordic countries: Norway, Sweden, Denmark and Iceland. Our aims were (i) to catalogue and characterise trends in research designs and research areas of these studies published over time and (ii) to describe how research involving nurses in Nordic countries has contributed to diabetes research overall. The larger goal of our analyses was to produce a comprehensive picture of this research in order to guide future studies in the field. We conducted a narrative literature review by systematically searching Medline, Medline in process, EMBASE, CINAHL, PsycINFO and Cochrane databases. These searches were limited to studies published between 1979 and 2009 that had an abstract available in English or a Nordic language. Two researchers independently selected studies for analysis, leading to the inclusion of 164 relevant publications for analysis. In summary, Nordic nurse researchers have contributed to the development of new knowledge in self-management of diabetes in childhood, adolescence and adulthood, and to some extent also in the treatment and care of diabetes foot ulcers. Future research may benefit from (i) larger nurse-led research programmes organised in networks in order to share knowledge and expertise across national groups and borders, (ii) more multidisciplinary collaborations in order to promote patient-centred care and (iii) further research directed towards improving the dissemination and implementation of research findings. Using complex intervention designs and a mix of research methods will enrich the research.

Keywords: literature review, nursing, research, type 1 diabetes, type 2 diabetes.

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Introduction

During the last three decades, advances in clinical care have given nursing practice an enhanced academic anchoring. Hallberg (1) advanced the idea that nurses can contribute importantly to a broader perspective of relevant questions raised in research. In addition, nurses contribute to building greater multidisciplinary research capacity in clinical practice. Research contributes substantially to evidence that promotes patient-centred care and to the maintenance of robust care plans for patient needs.

Along with the growth of professional and personal qualities needed to undertake significant nursing research, it is important to acknowledge that nurses have the ability to undertake high-quality nursing research and that this research directly benefits patients

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Marjolein M. Iversen, Bergen University College, Centre of Evidence-based Practice, Post Box 7030, 5020 Bergen, Norway. E-mail: miv@hib.no and affects care outcomes (2, 3). Nursing research involves sources that may well produce evidence for better practice, given that the studies address national health priorities, are systematic and are of good quality (4, 5). However, the state of nursing research in Europe needs to be improved as it is primarily characterised by descriptive studies that often poorly describe details of methodological design and research methods (6).

One area that needs increased attention is diabetes research. Diabetes prevalence is expected to rise substantially in the years to come, a trend that the Nordic countries are expected to follow. Globally, in 2013, about 382 million people had diabetes (7), and it is estimated that this number will increase substantially, reaching 592 million by 2035. According to the International Diabetes Federation Global Atlas (IDF), 1 in 10 adults and 15-20% of the older population served by community health care will have diabetes. These trends require an urgent response from healthcare professionals to discover new approaches to prevent this disease, as well as ways to reduce late complications from developing. Moreover, it is imperative to find new ways to promote a better quality of life for those living with the disease (7). Many people with diabetes have complex needs and often have more than one coexisting condition, such as obesity, foot problems, cardiovascular disease and other diabetes complications (7). Together, these issues also point to the need for increases in integrating knowledge.

In Nordic countries, similarities and differences across borders constitute a suitable context for investigating and discussing factors related to the development of diabetes nursing research. Moreover, cooperation in health, education and research has long been a Nordic tradition, one based on shared values that underpin the Nordic welfare model (8). This tradition dovetails well with how some researchers characterise nursing research. Goodman and Moule (9) describe how nursing research has a keen interest in what patients feel and experience, how nurses learn and develop throughout their careers and how multidisciplinary working and learning contributes to the care of patients. In a previous study, we discussed issues related to the development of diabetes nursing research in Nordic countries and the development of professional research competence and the pace of progress in building nursing research collaboration across national borders (10). Thus, the present study aims to review the entire body of scientific publications in the field of diabetes nursing research that has been conducted in four Nordic countries: Norway, Sweden, Denmark and Iceland. We sought (i) to describe the research designs and research areas of these studies in different time periods and (ii) to document the contribution of Nordic research studies in diabetes that has involved nurses for over 30 years. The results of this consideration generated an overall picture of the state of research in this field, so that we could uncover directions for further study.

Methods

Design

We carried out a narrative literature search for diabetes nursing research conducted in Nordic countries (Norway, Sweden, Denmark and Iceland) and published over three consecutive decades. A narrative literature review provides an examination of recent or current literature, which can cover a wide range of subjects at various levels of completeness and comprehensiveness. It may or may not include comprehensive searching and it may or may not include quality assessment. The synthesis in a narrative review is typically narrative and analysis may be chronological, conceptual, thematic, etc. (11).

Procedure

We were interested in identifying papers for which nurses had contributed as main or co-authors. Our search was restricted to articles published between 1 January 1979 and 31 December 2009 for studies done in Norway, Denmark or Iceland. For research done in Sweden, the comparable dates of publication were between 1 January 1979 and 24 November 2009. Electronic and manual searches were performed. For electronic searches, Medline, Medline in process, EMBASE (from 1980), CINAHL (from 1982), PsycINFO and Cochrane electronic databases were consulted. Both Medical Subject Headings (MeSH) and free text terms were used for restricting searches. Specific search terms were diabet*, nurs*, denmark*, danish*, iceland*, norw* swed*, adaptation, behaviour, behaviour mechanisms, care, coping, patient education, patient satisfaction and quality of life. These terms were also applied in combination with the Boolean operators AND or OR. We limited our selection of articles to those published in English, Danish, Icelandic, Norwegian or Swedish.

Two reviewers independently identified potentially relevant studies by reading titles and abstracts for more detailed information for each of the retrieved articles for the four Nordic countries. Through discussions by the two reviewers, consensus was achieved, and then the results were discussed further among the authors (MMI, MG, JL, BS, VZ and AKS). Moreover, one reviewer (MMI) scrutinised all the included articles. A manual search was done by reading the reference list of the retrieved papers and identifying additional publications missed by the electronic searches.

Study selection

In total, 6701 articles were retrieved initially. We excluded publications that were not peer-reviewed, did not report on a diabetes population or did not have nurses as main or co-authors. Of the 6701 articles, 505 were duplicates and thus were excluded. Inclusion criteria were articles in which nurses were the primary author or co-authors; and studies performed in Denmark, Iceland, Norway or Sweden. Studies of all kinds of research designs were included. Articles identified as potentially relevant according to their title and abstract were obtained in their entirety. One hundred and thirty-two publications met the inclusion criteria after careful scrutiny. In addition, 32 articles found in the manual search were included. Thus, in total, the present literature review included 164 publications (Fig. 1).

Data extraction

Information extracted from the literature search included the number of publications originating from each country and the time periods in which they had been published. The study design and methods of the studies were also extracted and categorised. Study designs were grouped as qualitative studies, cross-sectional and other descriptive studies, intervention studies or follow-up studies. Review articles emphasising methodological considerations were grouped together. The type of diabetes study population, research area and number of participants were also extracted and tallied.

Results

The majority of the included studies were published after the year 2000 (129/164), with 99 studies published within the last 5 years of the review period (2005–2009) (Table 1). There were only four articles published between 1979 and 1989, two from Norway and one each from Denmark and Sweden. Figure 1 shows that the largest proportions of publications were from Sweden (n = 86/164) and Norway (n = 45/164), and the smallest proportions were from Denmark (23/164) and Iceland (10/164).

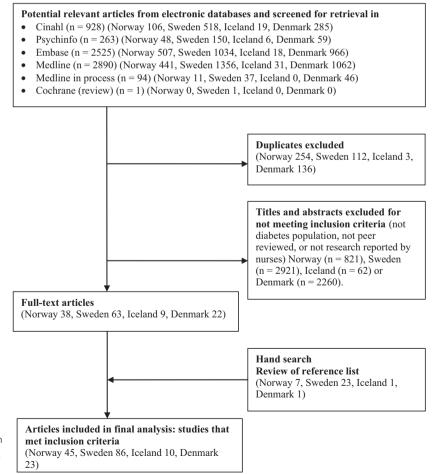


Figure 1 Flow diagram illustrating the selection process used for studies included in the present analysis (n = 164).

Table 1 Number of diabetes-related nursing studies conducted between 1979 and 2009 listed according to number and design

	Number of studies conducted per 5-year period (N = 164)						
Study design	1979–1984	1985–1989	1990–1994	1995–1999	2000–2004	2005–2009	
Qualitative studies (n = 49)			4	2	10	33	
Cross-sectional and other descriptive studies ($n = 71$)		1	11	7	19	33	
Intervention studies $(n = 14)$			1	1	2	10	
Follow-up studies ($n = 22$)		2	3	1	0	16	
Review articles and methodological considerations $n=8$)		1	1	0	1	5	

Research designs and research areas used during different time periods

Over the last three decades, the most commonly used designs were cross-sectional and other descriptive designs (n = 71) (Table 1). The majority (51/71) of the cross-sectional studies was published in 2000 or later. They were mainly authored by nurses in Sweden (25/51) and Norway (18/51). Fewer studies were authored by nurses in Denmark (5/51) and Iceland (3/51).

The particular areas of research addressed by the crosssectional studies changed over time. In the late 1970s and 1980s, the studies were aetiological in nature. In the 1990s, the research focus shifted to issues related to insulin administration (12, 13), development and testing of patient-reported instruments for use in psychosocial and health-related quality of life research (14-17), and quality of care studies on diabetes complications (18). From the new millennium and onward, more descriptive and cross-sectional research focused on children living with diabetes (19) and on adolescents (20). The focus on patient-reported outcomes grew further, starting in 2000 and thereafter. More than 50% of the cross-sectional studies were related to psychosocial aspects of the condition, health-related quality of life concerns and self-management (21-23). From 1979 to 2009, about 50% (36/ 71) of all publications focused on patient-reported outcomes, which have contributed to a better understanding of issues people deal with living with diabetes.

Up until 1999, most studies focused on type 1 diabetes, also known at that time as insulin-dependent diabetes mellitus (IDDM) (12, 14, 16, 17). More recently, diabetes was named as type 1 or type 2 diabetes (24–26) and the studies became more complex, as other comparison groups were also included (27, 28).

Qualitative designs were also used in nursing research of diabetes. These have generally examined how people with diabetes live with their condition. We identified 49 qualitative studies that explored people with diabetes' general perception of living with a chronic condition. These studies examined issues such as achieving harmony with oneself (29), dependence/independence (30), adherence/nonadherence, ways of accomplishing

improved glycaemic control (31), potential problems related to immigration and cross-cultural care (32), problems related to adolescence (33), problems related to life with foot ulcers (34), satisfaction with having foot ulcers treated at home (35), patient–provider relationships (36–39), challenges perceived during pregnancy and transition to motherhood (36, 40, 41). These qualitative studies have contributed to a better appreciation of the quality of daily care. Indeed, the new knowledge gained from these studies served as the foundation for changing practice and for guiding further research.

A few qualitative studies examined the lives of relatives of people with diabetes. A common theme identified by these studies involves the relatives' concern about their loved one's health as they strive to be involved in their care. For example, parents viewed daily living with their child as an ongoing learning process (42). Other common themes included lack of support from the healthcare sector and lack of tailor-made, health-promoting collaboration between the care team. Turkish/Kurdish parents of children with diabetes living in Denmark experienced difficulties in supporting their children due to different cultural backgrounds (43).

Randomised controlled trials (RCTs) were another type of design used in the included studies. Of the 14 articles reviewed that used a RCT, only one was published before 2004 (44). It evaluated the participation of young adults with type 1 diabetes in support groups. Over the next decade, our review shows that RCTs focused more on developing clinical practice. The RCTs included in this review investigated different aspects of psychosocial or educational interventions: four studied how education empowers people with diabetes (45-48), two looked at personal understanding of diabetes (49, 50), one investigated group-based counselling (51), and one used an RCT to study guided self-determination (GSD) (52). In one of these RCTs involving adolescents with diabetes, patient groups for education and support were supplemented by computer-assisted consultations (46). Two RCTs evaluated the effect of insulin treatment on glycaemic control and health-related quality of life (15) and compared the effect of multiple insulin injections to continuous insulin injections (53).

In 10 of 14 RCTs, the primary outcome was the effect on glycaemic control (15, 45–53). Almost all of the RCTs included patient-reported outcomes in the study design; only two did not (54, 55). Eleven RCTs used power calculations for determining the appropriate numbers of subjects (15, 45–54). The most common follow-up period was 6 months (47, 48, 51, 55), but four RCTs had follow-up periods of one to one and half years (45, 46, 49, 52) and one RCT had a 5-year follow-up period (50).

The remaining types of designs used in nursing research conducted on diabetes in Nordic countries were follow-up studies that used non-RCTs, cohort studies (retrospective or prospective), controlled before and after studies, and case series (uncontrolled longitudinal) studies. There were 22 articles on studies using these designs. Often the data came from hospital or national register databases and the focus was on quality of care or utilisation of healthcare services. For example, Cooper et al. (56) analysed HbA_{1c} levels and found that, in primary care situations in Norway in 2005, quality of care for people with type 2 diabetes in 33 healthcare centres improved (n = 2699), compared to the same primary care situations in 1995 (n = 1470). Prospective studies investigated how diabetes-related foot ulcers affected health-related quality of life and survival (27, 28). The studies employing other study designs reported how information technology, telemedicine and video consultations could be used to support foot ulcer treatment or self-management of these foot ailments (35, 57).

The contribution of nursing research studies in diabetes conducted in four Nordic countries

Nordic researchers in the study period of this review conducted a variety of studies within the field of self-management of diabetes in adults. Both people with diabetes' and providers' perspectives were explored with the aim of gaining a better understanding of barriers to empowerment that exists between people with poorly controlled diabetes and healthcare providers (HCPs). For instance, a review (58) used data mining techniques to reveal testing effects of educational interventions in 18 RCTs. They demonstrated that 17 out of 18 interventions reduced HbA_{1c} levels of people with diabetes. Based on this review, another RCT was conducted in which participants' responses to knowledge, self-care, empowerment and distress instruments guided the intervention (47). Substantial research was conducted in supporting people with poor glycaemic control. Three grounded theories provided an explanation for the barriers occurred between people with diabetes and HCPs connected with conflicting life-versus-disease perspectives (37). The relationships between people with diabetes and HCPs were seldom leveraged to exploit their potential in effecting change (38). Similarly, patterns of communication and reflection seldomly encouraged people with diabetes and HCPs to accomplish shared decision-making (39). These qualitative findings constituted the basis for developing a new method, GSD, which aimed to help people with diabetes and their HCPs to dissolve barriers. Subsequently, a RCT provided support for the efficacy of GSD by showing that people with diabetes improved their life skills and glycaemic control 1 year after participating in GSD group training (52).

Many studies have examined diabetes self-management during childhood and adolescence (20, 46, 48, 59, 60). The instrument called 'Check your health' was shown to be reliable and valid for use in teenagers with diabetes (61). Furthermore, empowerment education programmes were implemented and evaluated among young people with diabetes by using a wait-list group design. The authors of this study (61) suggested that group-based educational programmes tailored to young people with diabetes should be integrated into routine care (49). The general consensus opinion is that parents should be involved in all the diabetes-related education of their teenagers, with the purpose of increasing teamwork and decreasing control and conflict.

Through the use of a variety of study designs, Nordic nurse researchers have contributed to substantial research on treatment and care of diabetes foot ulcers (Table 2). Different research questions required the use of different study designs (Table 2). Cross-sectional studies reported the prevalence of foot ulcers, and the prevalence and occurrence of diabetes foot ulcer pain and its impact on health-related quality of life (24–26, 28). The quality of primary care for treating foot ulcers was inadequate, as only 25% of those with type 2 diabetes in Norway received a yearly foot check (62).

Two of the foot care studies investigated risk factors for foot ulcers and demographic and clinical characteristics associated with health-related quality of life in people with diabetes and foot ulcers (24, 28). Another study investigated preventive strategies in a large population-based cohort (63). One study compared health-related quality of life and psychosocial health of people with diabetes foot ulcers living in Scandinavian countries and in Tanzania, whereas another study compared health-related quality of life and psychosocial health of individuals with diabetes to those individuals without diabetes in the general population (28, 64). In summary, those with foot ulcers reported a lower perceived health-related quality of life compared to people with diabetes without foot ulcers and those in the general population (28).

Studies on foot ulcers using longitudinal study designs investigated wound healing, health-related quality of life changes and mortality rates (27, 65). Qualitative studies explored gender issues, the perspective of people with diabetes of living with lower extremity ulcers and diabetes and how these people perceived the nursing care they

Table 2 Example of core questions, scope and corresponding design in nursing research, examining the treatment and care of diabetes foot ulcers

Core question	Scope	Design	Publications	Scientific journal
How many subjects	Prevalence	Cross-sectional	Iversen et al. (24)	Scand J Public Health
have or had a diabetes		studies	Ribu et al. (26)	J Pain
foot ulcer?			Smide et al. (64)	J Clin Nurs
What is the likely course	Prognosis	Cohort studies	Ribu et al. (65)	J Diabetes Complications
of a diabetes foot ulcer?			Iversen et al. (27)	Diabetes Care
What did the subjects	Experiences/	Qualitative	Ribu, Wahl (34)	J Wound Care
experience because of	attitudes	studies	Hjelm et al. (66)	J Adv Nurs
their diabetes foot ulcers?			Clemensen et al. (57)	J Telemed Telecare
What can we do about diabetes foot ulcers?	Effects	Randomised controlled trials	Johansen et al. (55)	J Diabetes

received (34, 57, 66). These provided a more in-depth understanding of the burden of living with diabetes-related foot ulcers.

Discussion

The aim of the analysis in the present review was to generate an overall picture of research in the field of diabetes nursing within four Nordic countries over the last three decades. This is an important and relevant endeavour in order to determine directions for further meaningful study and policymaking. We observed a pronounced increase in published research since 1979, with the majority of studies being published after the year 2000. The research focus changed from mostly descriptive studies conducted in the late 1970s and 1980s to more complex studies and some RCT interventions conducted later on in the last decade. For most of the interventions, the follow-up time was rather short. Thus, there is a definite need for more longitudinal follow-up designs to be conducted. There is also a need to synthesise the results from qualitative studies in order to gain new knowledge of the patients' context and to broaden our understanding of managing and living with diabetes in the four Nordic countries.

Our review showed that the results of former studies examining the treatment and care of diabetes foot ulcers facilitated the design and execution of further intervention studies on alternative ways of treating and preventing diabetes foot ulcers in primary care (67). According to these studies, diabetes foot ulcers appear to be a marker of more severe illness, not only among people with diabetes in specialist care but also for those in primary care. Qualitative, cross-sectional and prospective studies investigated health-related quality of life of those with diabetes, thereby giving a public voice to a vulnerable group of people with diabetes-related foot ulcers who previously experienced life with fear and pain (34). Pilot studies described alternative ways of treating diabetes-

related foot ulcers, enabling hospital experts to monitor people with diabetes in their own homes (57). Further ongoing studies have been initiated with a greater focus on foot care and foot ulcer prevention for individuals with diabetes in primary health care (67).

The body of knowledge produced from the results of studies in the four Nordic countries on people with diabetes' subjective experiences can help diabetes nurses to develop interventions and measures applicable to clinical practice and to ensure that they have the expected outcomes (68, 69). According to Borbasi et al. (4), nursing research must make a significant contribution to enhancing the quality of care. More research is needed to identify more sensitive standardised and validated instruments for determining when, to what extent, to whom, by whom and under what circumstances interventions are beneficial. Nordic researchers have conducted many studies to assess the psychometric properties of translated standardised questionnaires. It is equally important to understand the complexity of dayto-day practice and the whole range of effects occurring in an intervention. According to the Medical Research Council (MRC) framework (70, 71), the key question that arises when evaluating complex interventions relates to how the intervention was developed, piloted and tested (72): What are the active ingredients of the intervention and how are they exerting their effects?

It has been pointed out that researchers often ask the wrong questions, conduct studies of poor methodological quality or fail to report research findings properly, or at all, resulting in 85% of healthcare research activities being a 'waste' (73). In a longer perspective, as underpinned in the framework of 'complex interventions', collaborative research across the Nordic countries might facilitate the use of results from modelling and pilot studies from some research groups to develop larger trials to evaluate treatment in more advanced design in multicentre RCTs. Nurse researchers need to move on to testing and evaluating interventions to advance clinical nursing

knowledge relevant to the work of clinicians and with direct benefit for patients. However, in the four Nordic countries, only 8.5% of the studies were RCT studies during this 30-year period. It is imperative to obtain new long-term funding to support all research phases, from modelling to dissemination of research findings (74). Also, action is needed to build stronger research networks across national borders. We have previously shown that only 14% of the studies included co-authors from another country (10).

The strength of this study is that the results generated an overall picture of the state of scientific publications in the field of diabetes nursing research which uncovered directions for further study. However, this study has limitations. One limitation was that we use the term 'Nordic countries'. The present study is a result from a novel network collaboration which consists of representatives from Norway, Sweden, Denmark and Iceland. Unfortunately, Finland was not represented. In the future, we intend to include and urge members from Finland into the existing network. Even though we searched multiple databases and used all relevant keywords, there is a possibility that we may have missed some studies, as our search criteria were broad in keeping with the review objective. Another limitation was the review's inclusive approach to study selection, including various methodologies and not considering quality assessment as a screening criterion. The only purpose was to achieve an overall picture, regardless of the quality of studies.

In conclusion, the directions and challenges for future diabetes research spearheaded by nurses in the four Nordic countries (Norway, Sweden, Denmark and Iceland) are threefold. First, we need to develop larger nurse-led research programmes that are organised in networks to

share knowledge and expertise across national groups and borders. Second, research within the field of diabetes nursing needs to be more multidisciplinary in nature. This will generate new evidence needed to promote patient-centred care to benefit people with diabetes. Third, further research needs to be directed towards improving the dissemination and implementation of research findings, which will likely be facilitated by employing complex interventions and a mix of research methods.

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Author contributions

Marjolein M. Iversen, Marit Graue, Janeth Leksell, Bibbi Smide, Vibeke Zoffmann and Arun K. Sigurdardottir were responsible for the study conception and design. All authors collected data and performed data analysis. Marit Graue and Marjolein M. Iversen were responsible for drafting the manuscript. All authors critically reviewed and approved the final version of this manuscript.

Ethical approval

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