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# **INFORMATION TO PEOPLE WITH DIABETES - ARE THERE PREFERENCES?**

A LITERATURE REVIEW

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Information and education is an essential part of diabetes treatment to ensure that people with diabetes will be able to live as well and with as few complications as possible. It is often up to the individual educator to give adequate information. Despite many possibilities, the patients' needs are not necessarily considered. The *objective* of the literature review was to see if patients had preferences to which diabetes information they receive as well as if they had preferences in which manner they receive diabetes information. The *method* was a systematic literature review based on the seven steps of Willman et al. [20]. Seven articles [21-27] were found and used. The literature searches were made in three databases; PubMed, CINAHL and ERIC. The *result* showed that patients did indeed have preferences to which information they received and in which manner they prefer to receive it. The patients wanted Individual, Specific and Reliable information and they wanted to receive it Continuously, Supportively, Easily and in Multiple Formats.

*Key words:* diabetes, information, patient, preferences

# INFORMATION TILL MÄNNISKOR MED DIABETES - FINNS DET PREFERENSER?

EN LITTERATURSTUDIE

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Information och undervisning är en viktig del av diabetesbehandlingen för att personer med diabetes skall kunna leva sina liv så gott och med så få komplikationer som möjligt. Det är mycket upp till den enskilda undervisaren att ge adekvat information. Trots många möjligheter, så är patienternas behov inte alltid tillgodosedda. *Syftet* med denna litteraturstudien var att se om patienter med diabetes hade preferenser om vilken diabetesinformation de tog emot liksom om de hade preferenser om på vilket sätt de tog emot den. *Metoden* var en systematik litteraturstudie, baserad på Willman et al. [20] Sju artiklar [21-27] identifierades och användes. Litteratursökningarna skedde i tre databaser; PubMed, CINAHL samt ERIC. *Resultatet* visade att patienterna hade både preferenser om vilken diabetes information de ville ta emot samt på vilket sätt de ville motta den. Patienterna ville ha individuell, specifik samt pålitlig diabetes information, och de ville motta denna information på följande sätt; fortlöpande, stödjande, utan svårigheter samt i olika Format.

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## **INTRODUCTION**

Some people contact the Pharmaceutical Industry in order to get answers to questions about diseases and treatment regimens. Inquiries, pertaining to medical or nursing issues, are forwarded to the Medical Information Department. I work as a Scientific Advisor with Medical Information in a pharmaceutical company. Part of my duties is to answer questions from patients and Health Care Professionals (HCPs). A surprisingly large amount of calls from patients or their next of kin (hereafter referred to as patients) were received over the past years. The mode of contact was by telephone, e-mail or internet sites. This gave rise to speculation on why the patients contacted the pharmaceutical company to receive information on diabetes. This sort of information would usually be handled by nurses and physicians, in primary care facilities, or at hospitals in order to enhance patient adaptation to help improve self-care and outcomes [1]. Did the patients feel the need to contact additional persons in order to obtain knowledge about their disease and treatment possibilities? Was the information they received from the health care system not adequate? Were there different and random levels of disease and treatment information given to persons with diabetes? What kind of information did the patients want or need? Were there preferences on how patients wanted to receive information and education? The author's preconceived idea was that there would be literature to confirm the notion that patients had preferred ways of being informed, e.g. face-to-face or written, and that they were in need of specific information when dealing with diabetes, e.g. blood glucose monitoring etc. This bachelor project investigated patient information to people with diabetes based on relevant literature.

## **BACKGROUND**

### **Diabetes - a chronic disease**

The latest diabetes global update from 2012 reveals that 371 million people worldwide live with diabetes [2]. Diabetes is a chronic, progressive disease, which occurs when the  $\beta$ -cells in the pancreas don't produce enough insulin, or when the body cannot effectively use the insulin it produces. This leads to an increased concentration of glucose in the blood (hyperglycaemia). In order to combat this, interventions in the form of life style changes and medicinal treatments are recommended [3]. Prolonged hyperglycaemia is associated with a risk of developing complications in the form of retinopathy (can lead to blindness), nephropathy (can lead to renal failure), neuropathy (can lead to amputations) and cardiovascular damage (can lead to heart disease and stroke) [3]. Strict adherence to self-care regimens is crucial for diabetes patients to live relatively normal lives. These complex routines must be practiced daily, and often for the rest of the person's life. It is not synonymous, though, to have knowledge about diabetes and to use this knowledge in practice. Compliance to treatment regimens and life-style changes is not always easy to handle. It is part of the health care team's work to educate and motivate the people in the best possible way [3].

## Diabetes and Education

It is recognized that early intervention minimises the risk for complications [4]. Standard European and American treatment guidelines encompass several steps, including life style changes, along with different medicinal regimens [4]. It is generally acknowledged that patient self-management is a crucial part of enhancing intervention efficacy. Recommendations include standardised general diabetes education for persons with Type 2 diabetes, with specific focus on dietary interventions and exercise as well as periodic counselling [4]. With additional drug treatment, the need for proper patient education regarding glucose monitoring, injection technique, drug storage, and recognition and initial treatment of hypoglycaemia are important. Certified diabetes educators are recommended for these tasks [4]. According to Hälso- och sjukvårdslagen (HSL) in Sweden, individually adapted disease information about health status, methods for examination, care and treatment possibilities is a part of a patient's rights [5].

According to the National Board of Health and Welfare in Sweden, Socialstyrelsen, the health care system's information to, and communication with the patient, is very important [6]. This is also supported by Socialstyrelsen's Description of Registered Nurses Competencies from 2005, where nurses should communicate with patients in a respectful, perceptive and empathic manner [7]. Good communication with patients, that leads to their participation in, and affects their care and treatment, is an elemental requirement in all health and care. The communication should be an integrated part of all care [6]. The patients' knowledge, understanding and insight are a prerequisite for their participation and influence over their health, care and treatment. Communication must be allowed to take time – and be reviewed over time [6]. That is to say, information must be updated, explained, repeated, and followed-up during the whole treatment process. Insufficient communication between patient and health care professionals is a potential risk for patient safety [6].

A meta-analysis and meta-regression performed in 2004 on the topic of diabetes patient education demonstrated that patient education interventions improved glycaemic control (lowering blood glucose levels) [8]. Interventions that had this positive effect on glucose levels included face-to-face interaction, cognitive teaching method and exercise content [8]. The improvement on glycaemic control in people who received self-care management was confirmed in a meta-analysis from 47 randomised trials from 2012 [9]. A systematic review from 2003 concluded that it was more effective to focus on patient behaviour - directly enhancing patient participation, than it was to focus on health care provider behaviour to change their consulting style in order to improve diabetes outcomes [1]. Patient behaviour focused interventions showed good efficacy and efficiency and improved patient self-care and diabetes outcomes [1]. Peel et al. concluded in an interview study, that patients wanted much more information at the point of diagnosis than previously thought [10]. Cheney discovered that diabetic adolescents wanted a structured education programme, specifically tailored to their needs [11]. In order to successfully implement a programme for young people with diabetes, recognition of the beliefs and values held by this generation should be respected [11]. Tessier focused on the diabetes education of the elderly patients, where consideration of the patients' physical and cognitive assets should be analysed in order to best aid [12]. Many patients with diabetes had a cognitive decline of 1.2 to 1.5 fold greater than those without diabetes and for this population it could pose

problems if the traditional method of learning was used [12]. A cross-national survey, from 2011, aiming to reveal patients' needs for care improvement, included eight countries across Europe and USA. 66% of the patients stated that, "knowing you can always contact your doctor if needed" and 35% of the patients stated that, "knowing where to get the newest information about diabetes" would increase their comfort and confidence about their diabetes [13].

### **Diabetes Education Format**

As seen above, it is well documented, that patients need and want to receive information and education on how to manage their diabetes. There are several different methods for educating patients. There is individual information, group education, written materials, internet sites, etc. Which mode that best covers the diabetes patients needs is unclear. The internet offers advantages, but also presents challenges. There is a considerable variety in the quality of diabetes patient education on web sites. This could pose problems since the users need to receive different levels of education [14]. Evidence-based concepts and customised content were some of the suggestions from a study of 53 diabetes web-sites offering diabetes patient education [14]. A literary review performed by the Swedish Council on Technology Assessment in Health Care, SBU, in 2009, revealed that there was a significant reduction in HbA1c with group-based education [15]. In contrast to this a study performed on the effect of group-based versus individual rehabilitation programmes in 2010, did not result in a greater advantage of group based education [16]. It presented similar or inferior glycaemic outcomes and needed more personnel resources compared with individual counselling [16]. Many patients feel that the information at hand, regarding diseases and treatments, often is very difficult to understand. Written information leaflets use difficult words, or use words that lead to misunderstandings. According to Thorsen et al., the patient leaflets and other materials that were distributed by the Danish Health and Medicines Authority and other health and care organizations, were too difficult to understand for lay persons (non-medically educated) [17]. In their study, often used words in medical texts were tested for comprehension. Only 10% of the tested words were understood correctly by 10% of the participants. None of the tested 143 words were correctly understood by at least 90% of the participants [17]. In this short review of education modes, no certain standard that meets all needs and preferences was found.

### **Theories of Learning**

In order for patients with diabetes to receive information that they can use in order to live satisfactorily with the disease (self-management), they need to be educated and this requires learning [1]. There are several theoretical schools of learning and several subgroups in each.

#### *Basic Theories of Learning*

The main schools of learning include Behaviourism, Cognitivism, Constructivism, and Humanism. Below is a short description of these four schools.

Behaviourism is a view where the learner is passive and reacts to environmental stimuli [18,19]. According to this source, behaviour is shaped by positive or negative reinforcement. Rewards increase the likelihood that the behaviour will happen again; in contrast punishment decreases the likelihood that it will be repeated [18,19].

Cognitivism focuses on the inner mental activities – opening the human mind is valuable and necessary for understanding how people learn [18]. Mental processes such as thinking, memory, knowing, and problem-solving need to be explored in order to fully describe learning [18,19].

Constructivism states that learning is an active process of constructing knowledge rather than acquiring it [18,19]. According to this theory, knowledge is constructed based on personal experiences and hypotheses of the environment, and learners continuously test these hypotheses through social negotiation [18,19]. Each person has a different interpretation and construction of the knowledge process [18,19].

Humanism focuses on the human freedom, dignity, and potential [18]. A central assumption of humanism is that people act with intentionality and values. Humanists also believe that it is necessary to study the person as a whole. The study of the self, motivation, and goals are topics of interest [18].

### *Nursing Theories and Learning*

In order to combine learning theories with patient education and treatment, it is important to look at nursing theories. Several nursing theories have evolved regarding nurse/patient relationships. One prominent theorist is Jean Watson that, through the years, developed her Theory of Human Caring and her Caritas Factors, listed below (Table 1). Watson wanted to give a theoretical contrast to the otherwise established notion of Curative (to cure) that was dominant in medical science [20]. The Carative Factors helped to define a framework to hold the discipline and profession of nursing. The Carative Processes were an extension of the Carative Factors and were intended to provide a more fluid language for understanding the deeper dimensions of living processes of human experiences. All of the Factors and Processes have relevant aspects for the process of nursing. The 7<sup>th</sup> Carative Factor (Promotion of transpersonal teaching-learning) and its complementary Carative Process (Engaging in genuine teaching-learning experiences that attend to whole person, their meaning; attempting to stay within the other’s frame of reference) focused on the aspect of learning [20]. In this specific context of patients’ preferences regarding receiving information and education, this factor became extremely relevant. According to Watson, learning was more than receiving information. It required a caring relationship as context for any teaching-learning, a relationship based on mutuality and cooperative interchange [20]. The educator needed to work from the patients’ frame of reference, finding what was meaningful and significant for him specifically, and ensuring that he was ready to receive the information. The educator became more of a coach, where the person became their own best teacher [20].

*Table 1. Jean Watson’s Carative Factors and Carative Processes [20]*

<b>Carative Factors</b>	<b>Carative Processes</b>
1. Humanistic –Altruistic Values.	1. Practicing Loving-kindness & Equanimity for self and other.
2. Instilling/enabling Faith & Hope.	2. Being authentically present to/enabling/sustaining/honouring deep belief system and subjective world of self/other.
3. Cultivation of Sensitivity to one’s self and other.	3. Cultivating of one’s own spiritual practices; deepening self-awareness, going beyond “ego self”.
4. Development of helping-trusting, human caring relationship.	4. Developing and sustaining a helping-trusting, authentic caring relationship.

5. Promotion and acceptance of expression of positive and negative feelings.	5. Being present to, and supportive of, the expression of positive and negative feelings as a connection with deeper spirit of self and the one-being-cared-for.
6. Systematic use of scientific (creative) problem-solving caring process.	6. Creatively using presence of self and all ways of knowing/multiple ways of Being/doing as part of the caring process; engaging in artistry of caring-healing practices.
<b>7. Promotion of transpersonal teaching-learning.</b>	<b>7. Engaging in genuine teaching-learning experiences that attend to whole person, their meaning; attempting to stay within other's frame of reference.</b>
8. Provision for a supportive, protective, and/or corrective mental, social, spiritual environment.	8. Creating healing environment at all levels (physical, non-physical, subtle environment) of energy and consciousness whereby wholeness, beauty, comfort, dignity and peace are potentiated.
9. Assistance with gratification of human needs.	9. Assisting with basic needs, with an intentional, caring consciousness of touching and working with embodied spirit of individual, honouring unity of Being; allowing for spiritual emergence.
10. Allowance for existential-phenomenological spiritual dimensions.	10. Opening and attending to spiritual-mysterious, unknown existential dimensions of life-death; attending to soul care for self and one- being- cared- for.

### *Focus on Humanism and Learning*

The learning theory that comes close to Watson's holistic nursing theory was Humanism. With this in mind, it is relevant to look closer at what the theory entails in more detail.

Humanism is a school of thought that believes human beings are different from other species and possess capabilities not found in animals [21]. Humanists, therefore, focus on the study of human needs and interests. A central thought is that human beings behave out of intention and values. This is in contrast to the beliefs of conditioning theorists, who believe that all behaviour is the result of the application of consequences. It is also in contrast to cognitive psychologists, who believe that the discovery of concepts or processing of information is a principal factor in human learning. Humanists also believe that it is necessary to study the person as a whole, especially as an individual grows and develops during his life. The study of the self, motivation, and goal-setting are also areas of special interest [21]. One purpose of humanism could be described as the development of autonomous people. In humanism, learning is student-centred and personalised, and the educator's role is that of a facilitator [18]. Affective and cognitive needs are the key, and the goal is to develop self-actualised people in a cooperative, supportive environment [18]. Key proponents of humanism include Carl Rogers and Abraham Maslow.

There are five basic objectives of the humanistic view of education [21]:

1. promote positive self-direction and independence
2. develop the ability to take responsibility for what is learned
3. develop creativity
4. curiosity
5. interest in the arts (primarily to develop the emotional system).

No other model or view of education places as much emphasis on these desired outcomes as the humanistic approach. Some basic principles of the humanistic approach that were used to develop the objectives, listed above, are [21]:

1. Students will learn best what they want and need to know.

2. Knowing how to learn is more important than acquiring a lot of knowledge.
3. Self-evaluation is the only meaningful evaluation of a student's work.
4. Feelings are as important as facts.
5. Students learn best in a non-threatening environment.

The learning theory of Humanism and Jean Watson's 7th Caritas Factor and Caritas Process correlate in many ways. Together, they form a basis on which to start a relationship between patient and carer, with the focus of medical and health education, in order to guide patients living with diabetes.

Physicians, nurses and diabetes educators all have a role in delivering information on diabetes management. The patients' needs for relevant information delivered in the manner in which they prefer can help ensure understanding and adherence to life-style changes and treatment regimens. It is therefore essential for the health care team to find out exactly what preferences people with diabetes have, when receiving information and education about this disease.

## **OBJECTIVE**

The objective of this report was, through systematic literature searching, to find articles about patients' preferences regarding diabetes information and diabetes education. Did patients have preferences to which kind of information about diabetes they received? Was there a preferred manner in which patients preferred to receive diabetes information?

## **METHOD**

A systematic method of finding and evaluating literature according to the seven steps from Statens beredning för medicinsk utvärdering (SBU) (1993) from Willman et al., page 57, was used [22]. These steps included the following;

1. Define the problem to be evaluated
2. Define the inclusion and exclusion criteria
3. Formulate a plan for the literature search
4. Perform the literature search and collect the studies that meet the inclusion criteria
5. Analyse the evidence from the individual studies
6. Compile the evidence
7. Formulate recommendations based on the quality of the evidence

The first step in the above plan required a definition of the problem to be evaluated, mentioned under "objective", above.

### **Data sources and searches**

Data for this literature review was found and collected in several steps [22] and is described below.

### *Inclusion and exclusion criteria*

The second step, the requirement of a definition of inclusion and exclusion criteria, was specified. These criteria are listed below.

#### **Inclusion criteria**

Inclusion criteria encompassed; full text published articles in the English and Scandinavian languages concerning both Type 1 and Type 2 diabetes mellitus, with no age limits, and disease information, patient-physician communication, patient education, and patient preferences.

#### **Exclusion criteria**

Exclusion criteria encompassed; abstracts, meetings, conference articles, books and press releases.

Articles that complied with the inclusion criteria stated above were included in the final selection group for analysis.

### *Literature Search*

According to the third and fourth steps, a plan for the literature search should be formulated and performed [22].

The general topic “information and education to persons with diabetes” was therefore more closely defined to “patients’ preferences in receiving information and education on managing diabetes”. This was further narrowed down to the initial search terms; *patient education, communication, diabetes mellitus, preferences*. In doing background searches it was difficult to differentiate between the use of the words “information” and “education” as it seems these terms are used interchangeably. From the literature, it was deduced that diabetes is a demanding disease, and so mere “information” on the subject was not specific enough. Dedicated “education” was the preferred term used. In order to attain relevant and broad enough literature, the term “education” was therefore chosen.

Pilot searches could aid the researcher to determine the general size of the hit list and thereby ensure that the chosen words catch a sufficient amount of articles [22]. Pilot searches in the PubMed database with the chosen search terms above, was therefore made. Similar terms, such as “self-management” and “support” were also tried. The searches revealed different results. The terms “support” and “self-management” did not result in the type of articles that was intended, so these were deleted completely. Neither did the term “communication”, and so this was also deleted. The search terms were edited and the final selection was as follows; *patient, education, preferences, "diabetes mellitus"*.

A search in PubMed was made, this time with the use of MeSH (Medical Subject Headings) terms. MeSH terms with relevant sub-headings were exploded and all terms were searched with the Boolean term “OR” between. A similar search in the CINAHL (Cumulative Index to Nursing and Allied Health Literature) database, with CINAHL Headings, was made to ensure a broad selection. Block searches with the above search terms were thereafter performed using the Boolean operator “AND” in the two databases. The result for the term diabetes mellitus did not result in any relevant hits in the CINAHL databases and so the term was broadened to “diabetes”. The searches resulted in an initial 233 articles in PubMed, this list

was reduced by filtering for full text articles in the Scandinavian languages as listed in the exclusion criteria above, resulting in 194 titles for initial review from the PubMed database. A similar search in CINAHL resulted in 18 titles. This rather small result encouraged further searches in a third database, ERIC (Education Resources Information Center) with focus on education with Thesaurus terms, in order to ensure a broader coverage. A similar search method with Boolean operators and block searches was made. This resulted in a further 27 articles for review. With a total of 239 articles found, an exclusion process was initiated to exclude articles with irrelevant titles, articles with irrelevant abstracts and articles with irrelevant text (see Appendix 1 for a summary of the search results and Appendix 2 for a more detailed flowchart process). Due to time restriction, a decision was made not to perform a manual search for further articles for analysis.

### **Article selection**

The initial aim of articles for final analysis was chosen to lie between 6-8 articles, based on guidance from teachers given being a single author to this project and due to the time restrictions allocated to this project.

After completed exclusion of all irrelevant articles in the total hit list (Appendix 2) a further assessment was completed by using a quality assessment protocol from Willman et al. [22]. The original protocols from Willman were translated from Swedish to English and edited to suit the objective of this report and an extra column for grading was added (see Appendices 3A and 3B). The articles were sorted in groups of “quality” – high (grade I), medium (grade II) and low (grade III), by a point system. Each individual question was given “1” point for a positive answer and “0” for a negative response. A percentage was then calculated from the total score to ensure an easier comparison as suggested by Willman et al. [22]. This method enhanced the possibility to weigh and compare the articles. Some articles contained both a qualitative and a quantitative part. Both sections were graded and given percentages. For those articles that contained different grading for the quantitative and qualitative sections, the higher grading was chosen as the overall grade to ensure that data from this section was included in the final analysis. The individual cut-off percentage was chosen by the author in order to further filter and ensure a high quality of articles for final analysis. Articles that received a percentage between 0-50% were given grade III, articles between 51-80% were given grade II, and finally, articles between 81-100% were given grade I. With this grading system, out of a total of 20 articles, 7 received grade I, 10 received grade II and 3 articles grade III. Only articles of grade I were chosen to be included in this report as the number was within the range of the initial 6-8 articles needed.

### **Data categorisation**

According to Willman et al., the fifth step in a systematic method of finding and evaluating literature, was to analyse the evidence from the individual studies [22]. This was done by the following method. The seven articles that met the inclusion criteria, objective and were of a high quality (grade I) were summarised by objectives, methods, outcomes and strengths and weaknesses in a table (Appendix 4) in order to further code and compare the results [20]. The articles were re-read and coded by a qualitative content analysis based on Graneheim & Lundman [23]. Similar words, wordings or meanings were clustered, and by using colour codes, put into different categories, defined by the author. A total of seven categories were found using this method. The seven categories were thereafter divided into

two main topics; what information the patients preferred to receive, and the manner in which they preferred to receive it.

## RESULT

The sixth step in the above seven-step plan for gathering and evaluating literature was to compile the evidence from the selected articles. The compilation of the evidence is listed below and the results are described more closely under each topic and can also be found in Appendix 4. The results were based upon seven studies, five with a qualitative method, and two that included both a qualitative and quantitative method. The results found were mainly taken from the qualitative section of the articles, as the quantitative section did not contain results that pertained to the objective in this report. The studies were performed in England (2), Sweden (2), USA (2), and Norway (1).

The articles displayed seven categories in total. Three categories fitted into the main topic that indicated what information the patients preferred. Four categories fitted into the other main topic that referred to in which manner they preferred to receive the information / education. The categories are listed below.

What information:

- Individual: adapted, flexible, tailored info, etc.
- Specific: info related to everyday life, practical advice- diets etc.
- Reliable: good medical skills from Info / HCPs, up-to date, trustworthy, from experts, etc.

In which manner:

- Continuously: follow-ups, re-education, continuity, same HCP etc.
- Supportively: emotional support from family, friends, peer groups, HCPs, being partners, no “controllers”, empathy, listened to, respected, holistic view, etc.
- Easily: easy and immediate access to info / HCPs, etc.
- Multiple Formats: clear, short, easy to understand, basic + additional, visual aids- graphs etc., internet, books, verbal or written, etc.

[24-30]

Five of the articles contained a theme that indicated that the patients preferred to receive Individual [24-27,29], Specific [24,25,26,29,30] and Reliable information [24,25,28-30].

Five of the articles contained a theme that indicated that they preferred to receive the information / education Continuously [25,27-30]. All seven articles indicated they preferred to receive it Supportively, three articles indicated they wanted it Easily [25,28,30]. Three articles mentioned in which manner or Format they wished to receive it [26,28,29].

### Preferred information

The results above indicated that patients indeed had preferences to which information they preferred.

### *Individual*

Five out of the seven articles described the patients' need for individual or personalised information. Information that was tailored to their needs and that gave meaning to which stage they were in, in the diabetes progression. Among the results, Cooper stated that patients preferred educational sessions, where they could negotiate the curriculum, by asking personal questions and thereby drive the sessions, in order to receive individual information [24]. In the study by Edwall et al. individual knowledge adjusted to self was trusted, because it had been effective in disease self-management [25]. In accordance with this, concern and confusion was the result when patients tested online educational tools that were not tailored to their individual preferences in Edwards' study. The patients stated that the information needed to be more flexible for a range of user needs [26]. Heisler described patients noting the importance of having HCPs devote time and effort to provide them with individual attention [27]. Finally Oftedal related to patients speaking warmly about how information was individualised to their personal circumstances and needs [29]. The studies showed that individual or individualised content is of the utmost importance to the patients.

### *Specific*

Five out of the seven articles described the patients' need for specific information for handling issues in everyday life as well as certain topics. Cooper noted that patients responded positively to the education course as it sought to integrate their personal experiences and that it was specifically related to everyday experiences [24]. Edwall concurred in her study that "information about health related to everyday life lead to inspiration and empowerment" [25]. Wikblad acknowledged the need for basic knowledge, especially knowledge that was applicable to daily life with diabetes [30]. In the Heisler study, even more specific everyday experiences were sought. The need for not only what to do but "how to do it" in relation to specific information on what to eat, recipes and cooking techniques, shopping for food and reading labels, etc. [27]. This specificity was again documented in Oftedal's study, where patients pointed out that they rarely received practical support in consultations, such as a hands-on course in diet, or how to make it easier to exercise, and this was missed greatly [29]. In all above, the patients' needs for specific information and education that they can relate to their life and living with diabetes was stressed throughout.

### *Reliable*

Five of the seven articles included categories that indicated the preference for reliable information. In this context, reliable means, the latest information that comes from a trustworthy source. Profit organisations or other general information sources were not trusted as much as when an educated person (doctor or nurse etc.) or other experts, delivered the information. Knowledge was an important factor when discussing medical treatments. For the patients, knowing that they were being treated according to the highest standards was very important. The need for information that was up-to-date and accurate ensured the patients, in their minds, that they received the best treatment. "Knowledge" and "expertise" were two words mentioned in the study by Cooper et al. [24] and access to a reliable partner was mentioned by Edwall [25]. Edwall also meant that patients were inspired and empowered by reliable expert advice, where they received trust-filled health support [25]. In the study by Longo et al., they quoted a patient saying; "I love the doctor and nurse of the diabetes center, the dietician and nurse educator. I know I can trust what they're telling me." [28] Oftedal concurred that profession-

als have knowledge and expertise about diabetes and its treatment and that patients explained that they need accuracy of information [29]. The need for consistency and up-to-date knowledge was also rated very highly [29]. According to Wikblad the patients demand good medical skills from the professionals [30]. Reliable information from a reliable source was a main topic amongst patients with diabetes.

### **Preferred manner**

As stated above, evidence drawn from the selected articles indicated that patients had preferences to which manner they received information and education. This will be dealt with below.

#### *Continuously*

Patients preferred to have a continuous dialogue with a specifically allocated HCP during the course of their diabetes disease and its progression. Five of the articles corroborated this point [25,27-30]. The need for continuous information was supported by Edwall that states “There was a need for regular support, to remind and increase patients’ understanding of the progression of the disease to manage the demands involved in adjusting treatment”[25]. Heisler briefly described the patients need for sustained and non-judgemental assistance to increase their motivation and confidence [27]. In the Longo study the results indicated that patients, even years after diabetes was diagnosed, expressed the need for periodic re-education as they realised how much there was to learn, encountered confusing or conflicting information or discovered that information changed over time [28]. Many patients mentioned that after the initial information, they often felt empty and left to their own devices. This emphasised the need for support on a continuous basis in addition to the regular check-ups offered as discussed by Oftedal et al. [29]. The educational follow-ups were an important factor for sustained knowledge, also stated by Wikblad et al. [30]. The need for a continuous process was essential when dealing with patients and their chronic disease.

#### *Supportively*

Diabetes patients also wanted the information to be given without prejudice and with caring and support. This common trait was found in all of the seven articles [24-30], indicating a very strong relationship with this statement. Such words as integrity, respect and compassion were seen as important traits of the tutor in Cooper’s study [24]. There was also a need for a supportive environment from groups or relatives, where empathy and understanding and accepting contributed greatly to learning [24]. Edwall talked about the patients’ need for being confirmed [25]. This meant being seen as a unique person and entailed being listened to and believed and remembered. This supportive relationship included information given without lecturing [25]. Information and education could at times be patronising and condescending. This method of delivering information was seen as very derogative and not very constructive to the learning process [26]. In Heisler’s study non-judgmental assistance was deemed important in relation to improving the patients’ ability to manage their diabetes [27]. There was also a great need for emotional support from professionals, family and other patients. Such words as “caring” and “the friendliness in her voice” was a motivating factor for continued progress [27]. Longo briefly stated that relatives and friends were amongst the most important sources of information and that their support was invaluable when discussing diabetes and its management [28]. An empathic approach was extremely important according to Oftedal et al. [29]. Patients de-

scribed empathy as understanding, listening and a holistic approach and this gave them a sense of trust and motivation [29]. Finally Wikblad discussed the topics of consideration and support, where she indicated that a meeting with the professionals had to imply more than measurements and prescriptions [30]. There had to be an interest in the patient as an individual person [30]. As seen above, the articles supported the notion of information and education given supportively.

### *Easily*

Easy access to the HCP or to the information regarding the patients specifically was another category. This was seen in three of the seven articles [25,28,30]. To have easy access to the information or HCPs was found to increase the feeling of safety as seen in Edwall's study, where they quoted a patient stating this; "knowing that the DNS (diabetes nurse specialist) is close by and can be contacted by telephone creates an enormous feeling of safety and in particular security" [25]. According to Longo patients consistently voiced a preference for information that was immediately accessible and easy to understand [28]. Wikblad summarised in one important category of "Accessibility" that "The patient must have continuous access to diabetes care" [30].

### *Multiple Formats*

Finally, the patients mentioned in which format (group education, face to face, written, audio or visual etc.) they wanted to receive information. There was no conclusive modus for in which format patients preferred to receive information. Some preferred face-to face information, others preferred focus-groups, while yet others wanted the information in written or audio form [28]. According to the study by Edwards et al., most of the patients wanted visual aids and found graphical representations helpful, such as bar charts etc. Others found information presented with smiley faces or thermometer-style images as patronising and unhelpful, and some even indicated information overload [26, 29]. In the Longo study, patients received both passive and active information about diabetes [28]. Some passive information was through media, such as newspapers and television, where they heard and read about the disease, without an active search for the subject. When looking actively for information, several methods were used, such as written information on the Internet, books, brochures and verbal information from relatives, friends and HCPs [28]. Also in this study and in the Oftedal study, many patients expressed that there was a risk for information overload, due to the volume and complexity of the information that could in some cases, in fact, have a paralysing effect which could reduce the motivation [28,29]. The need for clear and simple, easy to understand information was true for patients with both higher and lower levels of education. The format, although no conclusive evidence was found here, was not negligible.

## **DISCUSSION**

### **Method Discussion**

A systematic selection and evaluation was made according to the seven steps from Statens beredning för medicinsk utvärdering (SBU) (1993) from Willman et al., [22] page 57. The method described the requirement of defining several conditions, making restrictions and limitations in order to narrow the results. These definitions or restrictions could affect later steps in the process.

A primary definition included defining inclusion and exclusion criteria for the searches. A selection of such criteria meant choosing what to include, but also what to exclude. Such a selection may have affected later steps in the process. In this case, it was deemed that the best results to be made included full text peer reviewed articles, written in the English and Scandinavian languages. None of the articles found, were in any of the Scandinavian languages. This is not surprising, though, since most research performed in Scandinavia is mainly written in English. Excluding abstracts, meetings and press releases etc., meant a more narrow selection to choose from, but one which would ensure enough high quality data that could be evaluated and analysed.

The second restriction included the choice of search terms for the searches in the databases. The terms “self-management”, “support” and “communication” were disregarded after using searches which included these. The initial results indicated that the use of these terms did not enhance the hit list with useful articles. Although the use of such terms as “information” and “education” was reflected upon, the final choice could have influenced the final hit list.

Not only restrictions of inclusion criteria and search terms influenced the results. The choice of databases also had an influence; i.e.; how many databases were used, and which ones. In this case, initial searches were made in the PubMed and CINAHL databases, as they were known for the inclusion of literature concerning medical and nursing topics. PubMed included almost 95% of medical and nursing literature and approximately 65% of articles included in CINAHL concerned nursing [20]. It was speculated that the searches made in these two databases did not yield sufficient amounts of articles. A third database was therefore later included, ERIC, as this was specifically known to have topics on education. The intention with this choice was to ensure that the hit list would result in enough articles from which to make a qualified evaluation. The searches made in the ERIC database did not, unfortunately, make a serious contribution to the final list for analysis. The extra searches in this database did have value, though. Despite not yielding more useful data, the fact that no further articles were found could be an indication that the relevant articles were already found in the searches in the two previous databases. Manual searches were made initially to gather relevant background information on the diabetes topic and on laws and regulations. Such manual searches, by using already located articles reference lists to find further information along with textbooks, could be useful to gather “grey literature” [22]. This “grey literature” could aid in the retrieval of useful background information. No manual search was attempted to find articles for analysis. In this case, with the time restrictions writing this report, it was decided not to perform any such searches. This decision might have influenced the result, although most likely to a minor degree, as reference list searching leads to results from earlier and older publications.

There might have been many different studies within this research area and these studies might also have had different strengths and weaknesses and study quality. It would therefore be necessary to evaluate the articles [22]. In order to evaluate the articles in the final hit list, a quality assessment was made. A quality assessment protocol from Willman et al. [22] was used as basis and was translated and edited according to the specific requirements for this work. Since the protocol was edited by one person only, there may have been further questions that should have

been added or edited. The protocols used as basis, Appendices G and H from Willman et al. are recognised as valuable tools in the process of quality assessment, and should therefore be accepted as a sound basis for the assessment.

In order to enhance comparison of the final articles, the articles were graded and a result calculated in percentages. Although Willman et al. recommended this method, a scientific way of dividing the percentages into categories of high, medium and low was not described. The category-choices, therefore, became haphazard and were divided into thirds initially, as this seemed a natural choice. As a result, this construction resulted in too many articles with a high quality, and a revised division was set up. The revised version and cut-off percentage resulted in an adequate number of “high” quality articles. This haphazard way of conducting the grading and cut-off percentage might well have influenced the final selection for analysis. In future a more scientific or standardised method, if one exists, may be useful to minimise the discrepancies that arose with the above mentioned method.

The initial aim was to find 6-8 articles for final analysis. This number was primarily based on counsel received from teachers. This number was also chosen, partly due to the fact of a single author and due to restricted time allowed for this project. It cannot be denied that, had the aim of articles for analysis been higher, the results may have been altered. The results compiled in the seven articles analysed, had many similar categories, though, and so, further articles may have in fact strengthened these results further, as opposed to revealing significant different results. There was no doubt, however, that patients did have preferences to what information they received, and in which manner they preferred to receive it, since all articles analysed had this main topic in common. The number of articles analysed seem unlikely to have affected these results greatly.

The final restriction in this work entailed the summarising and coding of the articles. In the process of analysing the results found in the articles, the findings were summarised in a table [22]. The results were then clustered into seven different categories. These seven were divided into two overall objectives, “preferred information” and “preferred manner”. This was done solely by the author, and so, the selection and categorisation may not be found by others making a similar evaluation. A possible overrepresentation of categories or a possible exclusion of categories may have occurred. This issue could be minimised with the use of more than one “coder”.

The issues discussed above have been reflected upon and have given thought and inspiration to how other projects of a similar nature could be handled.

## **Result Discussion**

The seven selected articles [24-30] had several common sub-categories, with two main categories of “preferred information” and “preferred manner”. As stated in the Method Discussion, some criteria and choices selected in the process could have affected the outcomes of the results. The evidence in the above articles did not stand alone at this time. They were, in many cases, supported by other studies that reached similar conclusions, e.g. “Individual” [11,12], “Specific” [11,12] and “Continuously” [11,12,33]. Along with further studies, there were also basic theories on learning [18,19] and nursing [20] as well as laws and regulations [5,33] that supported many of the findings.

The seven articles found that patients indeed had preferences to what diabetes information they received and in which manner they received it [24-30]. Even though not all articles contained all of the above mentioned seven categories, the main topics of preferred information and preferred manner were evident. Also, when compiled, the categories that had been found were seen in many of the articles, which indicated that there indeed, existed a need for more precise diabetes information and more specific ways that patients preferred to receive this information.

### *Preferred information*

The need for individual or individualised information seemed to be an almost universal trait. Not only was it noted in five of the seven articles [24-27,29] it could be supported by the Learning theory based on Humanism, where learning is student-centred and personalised [18]. The concept of an individualised framework for the education of ill people in general, could also be related to Watson's nursing ideology, where the educator needed to work from the patients' frame of reference, finding what was meaningful for him specifically [20]. This concept of individuality was seen in many articles, and was not only applicable to adults, it related to all age-groups. Adolescent diabetics, who were under guardianship from parents or other care-takers were not satisfied with standardised education. They wanted a structured education program that was tailored to their needs [11]. This notion also applied to elderly persons who had been diagnosed with diabetes. The traditional treatment process usually requires mobility as well as other cognitive abilities to manage exercise programs and blood glucose measurements etc. Elderly may have limitations regarding such abilities and need more flexible and adapted information. According to Tessier in an article concerning diabetes and the elderly, the methodology of teaching should be adapted to the existing physical and cognitive handicaps in this population [12]. As stated earlier, individually adapted disease information about health status, methods for examination, care and treatment possibilities is a part of a patient's rights according to Hälso- och sjukvårdslagen in Sweden [5]. This law makes it even more crucial to ensure that the concept of individual information is enforced in all cases where patients need to be informed of their medical situation. I think it is surprising to find that in today's individualised society, that this need apparently is not yet met in the health sector. When so many businesses in the western society is based on the need to meet the customers' needs, why is this an issue when it comes to "customers" that are ill? It is an interesting concept, though, that many pay taxes or private health insurance to receive medical treatment, but the basic rights stated in HSL may not be met, when looking at patients with diabetes. There are already discussions about individualised health care, even down to the patient's genetic profile. This future health care system would need to include individualised information – not only individualised treatment. Fierz talked about data systems, where personal medical data is stored and made accessible when medical decisions are to be made [31]. According to him, information could not stand alone, though, it needed to be evaluated, planned and acted upon with a common goal within a strategy. For this to take place, information had to be made accessible and the information had to be communicated and most importantly, to be understood, which meant patient education and professional education are key for this to be a success [31]. Whether or not this individualised health care future will come, today's patients already crave to be informed on an individual basis, and this must be considered in today's health care system, not only in theory, but also in practice.

Some of the articles described the patients' need for specific information for handling issues in everyday life and everyday experiences [24,25,27,29,30]. This idea of topics that relate to everyday experiences could also be found in other literature. Peel found that some patients wanted to be given simple instructions on what to do and what not to do, especially about lifestyle modifications, such as dietary regimens [10]. Cheney found that adolescents wanted to engage in, for example, dietary freedom and therefore needed instruction on how to manage such difficult situations, that usually were considered banned under the diabetes topic [11]. Tessier supported the idea of transferring knowledge on specific and actual problems in diabetes. Specific courses on insulin treatment, hypoglycaemia management as well as foot care was deemed essential, since many elderly patients are at risk of lower limb amputation [12]. This "specific information" could not be generalised from the above evidence. That is to say, although there were several topics that are "must have" information when dealing with diabetes, (such as blood glucose measurements, dietary needs etc.), patients did not give a consensus answer about which of the topics that they preferred or needed to receive information on. There seemed to be a need for specific topics, but they were very individual. The fact that patients asked for specific information about topics that concern them was not surprising and could be related to the learning school of Humanism, where one of the topics stated that students learn best what they want and need to know [21]. Current information strategies in diabetes health care are very general, where every person with diabetes should be informed that they should exercise, eat healthy and measure their blood sugar levels regularly. I believe that this strategy is too general and not always successful. Instead of generalising the topics, a specific recommendation could be made, one that relates to his or her concerns or needs. I think that discussing the patients' specific needs "here and now" is very important, in order to meet their needs. Exercise for a particular patient may not be an issue today, but could well become one in six months' time. Even for two diabetes patients with need for exercise information, one might be fit and used to exercise several times a week, while the other may never have felt a need for or interest in exercise. Both patients may require exercise information but due to their different needs, knowledge and interest in exercise, the information must be brought to them in a very different and specific manner to be perceived helpful. I also believe that this means discussing different specific exercise programs in depth in order to find a regimen that fits the individual, when the time is right. I believe that individual and specific information go hand in hand in practice, but from a theoretical point of view they are different. Individual information may for example be based on a given patient's need for exercise, but be delivered in a generalised manner. Specific information may for example be based on how a diabetes patient can plan a jogging regimen to help exercise, but be communicated to a patient group where the specific information is perceived irrelevant. I think that helpful diabetes information is both individual, i.e., with basis in the patient's needs, and specific in the sense of being operational.

The need for reliable information that is up-to-date and accurate ensures that the patients receive the best possible treatment at any given time, which was seen in five articles [24,25,28-30]. Reliable information supplied by a reliable source might seem straight forward, when dealing with medical information coming from an HCP. From my own experience, this is not always the truth. If the HCP has not updated his or her knowledge in the diabetes area over the past few years, the information supplied to his or her patients may be outdated. This may result in sub-

optimal treatment regimens, possibly leading to issues with patient safety, where the patients suffer from complications due to late or missing treatment. This is in direct contrast to the law on patient safety (2010:659), where it explicitly states that the caregiver should take adequate measurements to prevent harm or injury to their patients [32]. This reflects the need for a knowledgeable, trustworthy and reliable partner to deliver the information. This was also found by Hajos et al., where 35% of patients with diabetes stated that they would feel more confident and comfortable about their diabetes if they knew where to get the newest information about diabetes [13]. Lawton found that some patients were disappointed to be transferred from the hospital to primary care, since they regarded the physicians here as less knowledgeable, because they could never acquire the same level of expertise as the specialists at the hospitals [33]. This could also be related to Socialstyrelsen that mentions that information must be updated and followed-up during the whole treatment process, in *Nationella riktlinjer för diabetesvården 2010* [6]. I believe that delivering reliable information is crucial. It is necessary for caregivers and any system in which they work, to allow the time and the effort it takes to be updated in order to ensure the highest quality of patient care and therefore also patient safety. It may be a time-consuming and difficult task for all HCPs to stay updated all the time. This might be eased if HCPs, for example, were able to take turns with attending lectures or other educational sessions, coordinated by a registered nurse, and then reported the results to the remaining nurses. Written folders or short summaries could also be made, so that all relevant educators have access to the latest information.

### *Preferred manner*

Patients preferred to have a continuous dialogue with a specifically allocated HCP during the course of their diabetes disease and its progression as seen in five of the articles [25,27-30]. This statement was supported by a study by Lawton et al. that also had similar results, where patients wanted to meet the same HCP who knew their background, to be treated by people you are familiar with and people who know you [33]. Tessier also noted in his article, that diabetes education should be viewed as a long term process [12]. The long-term process was again supported by Cheney that confirmed that adolescents also found follow-up very important in order to offer support, reassurance and guidance [11]. Not only studies found this need for continuous information. It is also an essential part of the laws and regulations stipulated by Socialstyrelsen and Hälso- och sjukvårdslagen in Sweden. Socialstyrelsen states that communication must be allowed to take time – and be reviewed over time. Information must be repeated and followed-up during the whole treatment process [6]. HSL demands that the patients' needs for continuity and safety in the health care system are fulfilled [5]. I believe this need for continuous information is an important issue in the current health care system. It would be practically impossible to ensure that the patient only has contact with one person during a lifetime management of diabetes. The HCP could move, be ill or even die. A compromise, where instead of just one HCP having responsibility, a health care team could be set up. This is already an integrated part of the National Guidelines for diabetes care in Sweden [6]. This demands more in-depth documentation and increased communication between the HCPs, but this could result in a flexible team that could support the patient on a more continuous basis, since more personnel would be involved. There are always practical and economic issues with changing current set-ups, but this could also be seen as an investment in the future, where patients feel safe in the health care environment and suffi-

ciently informed to live a good quality life, possibly with fewer complications and thereby potential savings in the public health system.

Diabetes patients also wanted the information to be given without prejudice and with caring and support as seen in all of the seven articles [24-30]. This need for a supportive communication was also mentioned in a study by Hajos et al. and included both family and HCPs. [13]. Support and caring is an emotional aspect of education, and some might not deem this as essential when discussing medical education. However, supportive and caring education is directly related to Humanism and education. One basic principle of the humanistic approach is that feelings are as important as facts [21]. Caring and support is also an important aspect of nursing and can be related to Watson's nursing theory, where learning was more than receiving information. It required a caring relationship, a relationship based on mutuality and reciprocity [20]. Watson mentioned in her third Carative Factor, "Development of helping-trusting, human caring relationship", that it was important for nurses to be sensitive to self by looking into one-self and to explore one's own feelings [20]. By being sensitive to oneself, it would be easier to be sensitive to others, and nurses who managed this were more able to learn about the other's view of the world, which then increased concern for the other's comfort, recovery and wellness. In her fourth Carative Factor; "Promotion and acceptance of expression of positive and negative feelings", she mentioned that nurses needed to focus on feelings and emotional aspects of an event [20]. By also listening to and honouring another person's feelings, nurses could honour the patient's story, which held meaning and importance for them and their healing [20]. These Carative Factors could aid nurses in the development of the caring and support that is necessary to promote a non-judgemental attitude when educating the patients. In practice this may be quite natural for some, but for others may pose a challenge. I believe it is important to be more aware of one's own reactions as well as listening more closely to the patient's reactions. This may take time, but is well worth the investment, even when it might be seen in connection to such a trivial thing as information to a patient about a very basic issue.

Easy access to their HCP or to the information regarding them specifically was yet another category and found in three of the seven articles [25,28,30]. Frustration with having to wait to get information on different diabetes issues was seen in many studies. To be able to quickly get an answer was important. This was also corroborated in the study by Hajos et al., where easy access, knowing that you can always contact your doctor if needed, was highly valued by patients [13]. This could also be related to HSL, where it demands that the health and care system should be managed in such a way that the quality needs are met. One of the demands is that it be easily accessible [5]. For many, accessibility may seem to be a trivial matter in today's technological world, where everything is digitalised and on the Internet. I believe the problem yet remains, especially seen in the light of the above categories of "Reliable" and "Individual". Is information found on the Internet updated and trustworthy? It may be easily accessible, but can it be trusted as a reliable source? Is it applicable to me as an individual? Is it specific and operational? Many questions arise and the answers are yet not found. To me, it seems as if in most cases, it remains up to the patient to sift through the myriad of pages on diabetes and treatments on the Internet to try to find information that they need. The alternative is to wait for weeks for an appointment with their health care professional. In the economic situation the world and health care systems are in currently, cut-backs are everyday issues, leading to more patients to

handle and less time with each patient. In my opinion, for HCPs to be available for “drop-in consultations” at the will of the patients’ is not realistic in most cases, since waiting lists and shortages of nurses is a never-ending problem. I believe that the development of reliable information on trusted Internet sites, that are updated regularly with evidence based material, preferably with a usable interface that takes individual needs into consideration, would be a step in the right direction.

Finally, the patients mentioned in which format (group education, face to face, written, via telephone, web-sites etc.) they wanted to receive information in three of the articles [26,28,29]. There was no conclusive modus for in which format patients preferred to receive information. Some preferred face-to face information, others preferred focus-groups, while yet others wanted the information in written or audio form. More still, were satisfied with web-based learning, where health information was introduced via the internet. The format, although no conclusive evidence was found here, was not negligible. It still was an important factor and could in part be related to the “individual” topic mentioned above - the need for individualised information. All people have different ways of absorbing information, or learning [34]. Some people had a visual learning style and preferred to learning aids such as posters, videos, graphs and pictures. Some had an auditory learning style and they respond well to verbal information such as stories and descriptive language. Another category of learners had a reading learning style. The assessment of whether a person was a reading learning style also included the need to review the person’s literacy level [34]. These individuals did well with written information in lists, pamphlets and manuals. The fourth learning style was the kinaesthetic one. These persons preferred to attach new learning to a base they already knew or had experienced. A need to connect their current situation to previous knowledge or similar situations they know of was the best way to reach them. There are several tools in which to best assess people’s learning styles. One of these was the VARK (visual, auditory, read and kinaesthetic) inventory, created by Neil Fleming in 1987 [34]. It included questionnaires designed to identify individual learning styles and instructional preferences. I believe that learning disabilities, such as dyslexia, impaired hearing or impaired sight would also affect the patient considerably. It is essential to try to understand the individual preferences for format and therefore the initial contact information should also include basic questions on handicaps or preferences for receipt of information.

To summarise; individualised, specific and reliable information, given on a continuous basis and in a supportive manner, with easy access to the information presented in multiple formats, was what the diabetic patient preferred. There were many arguments for attaining this result, based not only on the articles themselves, but also on legislation, and basic learning and nursing theories. The author’s preconceived idea that there would be literature to confirm the notion that patients had preferred ways of being informed and that they were in need of specific information when dealing with diabetes, was confirmed. The hope of retrieving very specific data from the articles, (that patients preferred information on blood glucose measurements or that face-to-face sessions were the most preferred), could not be established in this report. This lack of proof is not disheartening, though, but instead shows that patients are individual persons, with individual needs and this should always be kept in mind, when working professionally. To try to seek information and understanding about the patient’s situation could help guide the HCP to focus on the patient’s areas of needs and preferences. I believe

the effort may take some extra time, but may be repaid greatly, both in the short and long term. It would be an investment that could greatly affect the quality of health care in a most positive way.

## **CONCLUSION AND FUTURE IMPLICATIONS**

The seventh and final step of Willman's seven step method [22] for finding and evaluating literature was the requirement of recommendations based on the evidence found in the literature.

This report concluded that there was evidence in the literature that people with diabetes had preferences to what information they receive, and also, in which manner they wanted to receive it. Individualised, specific and reliable information, given on a continuous basis and in a supportive manner, was what the diabetic patients preferred. Easy access to the information that was presented in different formats was also a factor. Everyone has individual needs and preferences, and it is essential to move towards patient-centered care, in order to meet these demands. It is important to remember to try to gather information about your patients, to ask them what their information needs are and put yourself in their shoes. Some patients may be very conscious of their preferences, others may need a helping hand to understand how we, as health care professionals, best can help patients with supporting them with the information they need to live as fulfilling lives as possible with the diseases they may have.

Further studies and compilations on this topic would possibly be able to clarify if there are useful tools or methods HCPs could use in order to best gather information about their patients' preferences. Such tools or methods could give support when dealing with the topic of giving individualised and specific diabetes information.

Other studies could focus on whether or not information given according to the preferences mentioned in this report could improve the quality of life for the patients or maybe even improve patient outcomes.

It would also be interesting to divulge if improved information would be more expensive or instead cut costs for the health care systems. Theoretically, fewer complications would occur if patients received information they needed, and in the way they preferred, and were able to act upon this information, thus increasing compliance and thereby improving outcomes.

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# APPENDIX 1

## Searches

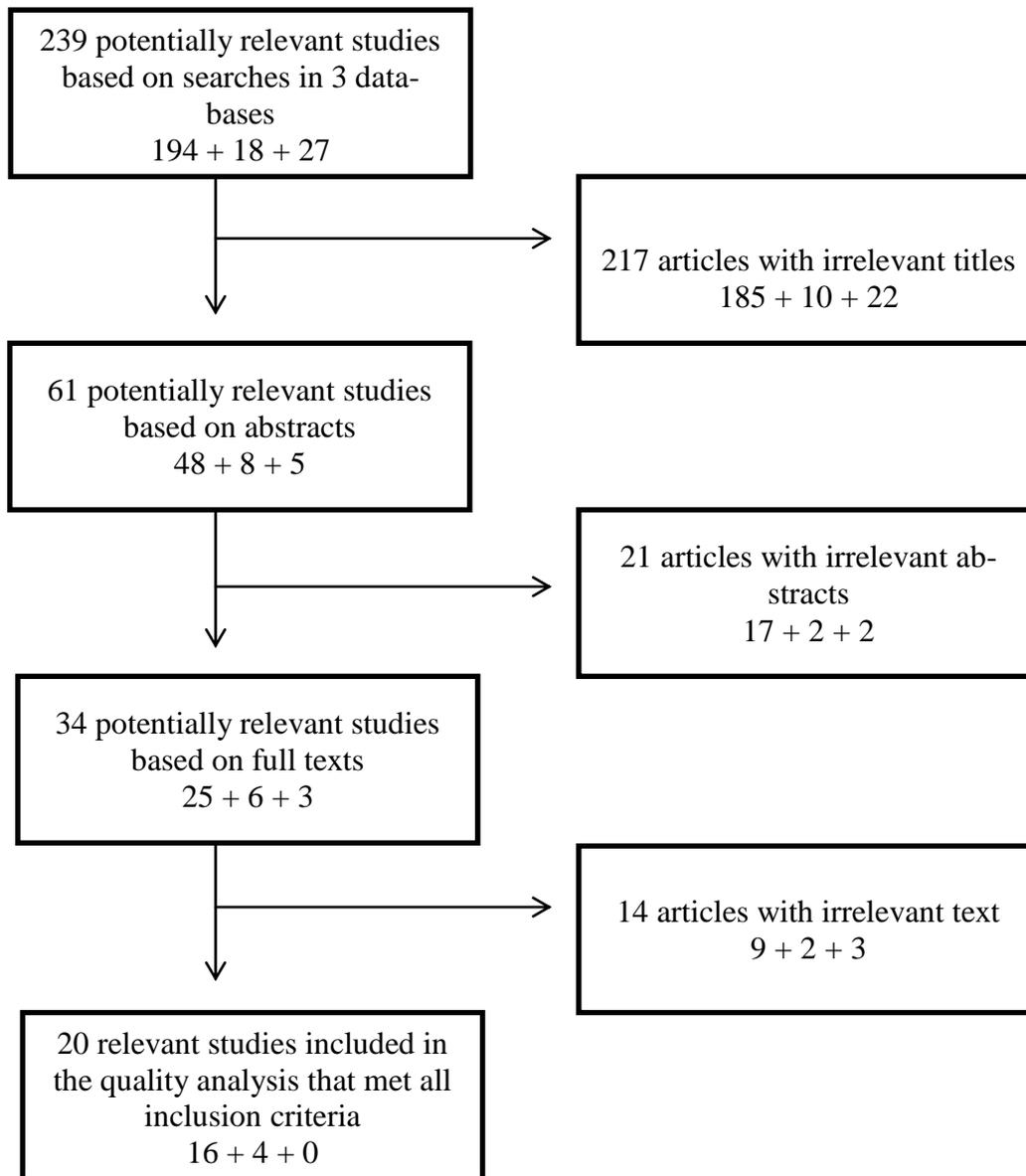
Searches in PubMed, CINAHL and ERIC

Databases	Search Date	MeSH/ Subject Headings/ Thesaurus/ Expanders/ Boolean/ Phrase	Filters	Final Hits	Reviewed titles	Reviewed abstracts	Reviewed full text	Used articles
PubMed	2013-01-07	Diabetes Mellitus AND Patients AND Patient preference AND Education	Full text, English, Swedish, Danish, Norwegian	194	48	25	16	5
CINAHL	2013-01-07	Diabetes AND Patients AND Patient preference AND Education	Full text, PDF Full text, English, Swedish, Danish, Norwegian, diabetic patients	18	8	6	4	2
ERIC	2013-01-11	Diabetes Mellitus AND Patients AND Patient preference AND Education	Full text, Peer reviewed, English, (no Scandinavian languages found)	27	5	3	0	0



## APPENDIX 2

Flowchart of the process of article selection according to inclusion criteria.  
Search results from PubMed, CINAHL and ERIC resp.



## APPENDIX 3A

Protocol for quality assessment of studies with qualitative method, based on Willman et al. [20], translated and edited by Sofia Jacobsen

<i>Description of the study, method etc.</i>				Points
Related to Information/Education?	Yes	No	Unknown	
Is there an objective?	Yes	No	Unknown	
Patient characteristics	N	Age	M/F	
<i>Is the context presented?</i>	Yes	No	Unknown	
<i>Ethical reasoning?</i>	Yes	No	Unknown	
<i>Selection</i>				
Relevant?	Yes	No	Unknown	
<i>Method</i>				
Selection thoroughly described?	Yes	No	Unknown	
Data collection thoroughly described?	Yes	No	Unknown	
Analysis thoroughly described?	Yes	No	Unknown	
<i>Validity</i>				
Is the result logical?	Yes	No	Unknown	
Enough data?	Yes	No	Unknown	
Enough analysis?	Yes	No	Unknown	
<i>Communication</i>				
Is the result clearly presented?	Yes	No	Unknown	
Is the result presented in relation to a theoretic reference?	Yes	No	Unknown	
Does the article answer my objective?	Yes	No	Unknown	
Are results related to patients' preferences?	Yes	No	Unknown	
Can answers to questions be found?	Yes	No	Unknown	

### Main findings

Which experience, preference is described? Is the analysis adequate?

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### Summary of the quality assessment

Total points/ Percentage	High	Medium	Low

### Comments

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## APPENDIX 3B

Protocol for quality assessment of studies with quantitative method, RCT & CCT based on Willman et al. [20], translated and edited by Sofia Jacobsen

<i>Description of the study</i>	Yes	No	Unknown	Points
Related to Information/Education?	Yes	No	Unknown	
Study method	RCT	CCT	Unknown	
Patient characteristics	N	Age	M/F	
<i>Criteria for inclusion/exclusion</i>				
Adequate inclusion/exclusion?	Yes	No	Unknown	
<i>Intervention</i>				
<i>Main objective of study</i>				
Primary endpoints				
Secondary endpoints				
<i>Selection</i>				
Described?	Yes	No	Unknown	
Representative selection?	Yes	No	Unknown	
<i>Dropouts</i>				
Is the analysis of dropouts described?	Yes	No	Unknown	
Is the size of dropouts described?	Yes	No	Unknown	
<i>Ethical reasoning?</i>	Yes	No	Unknown	
<i>Results</i>				
Are the results plausible?	Yes	No	Unknown	
Can the result be generalised?	Yes	No	Unknown	
Does the article answer my objective?	Yes	No	Unknown	
Are results related to patients' preferences?	Yes	No	Unknown	
Can answers to questions be found?	Yes	No	Unknown	

### Main findings

How large was the effect? Statistical significance? Clinical significance?

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### Summary of the quality assessment

Total points/ Percentage	High	Medium	Low
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### Comments

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# APPENDIX 4

## Article summary

Table 2. Summary table of seven relevant articles for analysis

Author, Journal, Year, Country	Title	Objective	Method / design, participants (n)	Main results	Scientific quality
Cooper HC et al., Health Education Research, 2003, England	Patients' perspectives on diabetes health care education	To see if participation in education intervention impacted patients' beliefs, led to changes in self-care, and had impact on blood glucose.	RCT, blinded, Education Intervention, Semi-structured interview- 10 focus groups, taped and transcribed, analysis inspired by Miles and Huberman, Quantitative + Qualitative, learning theory to practice, 14 months, n=89	<p>Quan.: Significant changes in blood glucose (<math>p=0.005</math>) at 6 mos. Significant changes in attitudes (<math>p=0.005</math>) at 6 mos., (<math>p=0.01</math>) at 12 mos. Significant changes in perceptions of self-care (<math>p=0.02</math>) at 6 mos. Positive improvements in diet and exercise- not significant.</p> <p>Qual.: Cat.1 1. Tutor's expertise- (respect, trust, empathy, knowledge) 2. Negotiated curriculum- (individualised info) 3. Experiential learning- (integrate personal experiences) 4. Group support- (between equals, social) Cat. 2 1. Different disease stages - (different info needs) 2. Aligning needs to match interventions</p>	<p>Qual. 88% (I) Quan. 88% (I)</p>
Edwall L-L et al., Journal of Clinical Nursing, 2008, Sweden	The lived experience of the diabetes nurse specialist regular check-ups, as narrated by patients with type 2 diabetes	To elucidate the lived experience of diabetes check-ups among patients with type 2 diabetes	Narrative interviews (35-90 mins.) interpretive analysis method inspired by Ricoeur, taped and transcribed, Qualitative, phenomenological-hermeneutic method, 2 primary care units, n=20	<p>4 themes: 1. Being confirmed- (unique person, listened to and believed)- same HCP 2. Guided within disease- (reminded and updated- trust-filled conditions, info related to everyday life, recurrent, adapted info) 3. Confident and independent- (regular support, understood and trusted) 4. Being relieved- (safe and secure, not alone- HCP close by, easily contacted- access to reliable partner)</p>	<p>Qual. 94% (I)</p>

Author, Journal, Year, Country	Title	Objective	Method / design, participants (n)	Main results	Scientific quality
Edwards A et al., Patient Education and Counseling, 2006, England	Presenting risk information to people with diabetes: Evaluating effects and preferences for different formats by a web-based randomised controlled trial	Evaluation of different risk presentation formats on people with type 2 diabetes.	RCT + online, 4 Education Intervention groups, 1 control group, Quantitative + qualitative, written questionnaire, n=256	<p>Quan.: No statistical significance on formats</p> <p>Qual.: Individual needs and preferences Numerical info- graphs, visual aids, simple, short format, clear info Not too much info Not too patronising info, not too basic, not too repetitive, avoid jargon Need flexible info-( real life choices) Tailored to wide range of pts.</p>	Qual. 88% (I) Quan. 71% (II)
Heisler M et al., AM J Prev Med, 2009, USA	Participants' Assessments of the Effects of a Community Health Worker Intervention on Their Diabetes Self-Management and Interactions with Healthcare Providers	Patients' assessments of Health worker intervention incl. education on diabetes care	Qualitative descriptive study, semi-structured telephone interviews (60-90 mins.) taped and transcribed, consensus in coding, n=40	<p>Need rationales that connect self-management to outcomes</p> <p>Need education and training on specific needs</p> <p>Need sustained, non-judgmental assistance</p> <p>Need social and peer support</p> <p>Specific info on diet etc. "How to do it"</p> <p>Individual attention</p> <p>Review and reinforce info in-depth, specific examples to meet behavioural goals</p> <p>Emotional support from HCPs and groups</p>	Qual. 88% (I)

Author, Journal, Year, Country	Title	Objective	Method / design, participants (n)	Main results	Scientific quality
Longo D et al., Annals of Family Medicine, 2010, USA	Health information Seeking, Receipt, and Use in Diabetes Self-Management	To identify how individuals with diabetes seek and use health care information	Qualitative, interviews, 9 focus groups with moderator, observers took notes, questionnaires, coded core questions, n=46	<ol style="list-style-type: none"> <li>1. Passive info- (TV, newspaper, talk shows)</li> <li>2. Active info- (Internet, book, brochures, magazines, cook-books, verbal + printed, info via telephone) Need for periodic info-re-education - info changes over time, Conflicting or confusing info,  </li> <li>3. Relationships help understand and use info- info from HCPs relatives and friends</li> <li>4. HCP help to understand and manage info- HCPs are trustworthy, information overload, volume and complexity - paralyses</li> <li>5. Literacy important- Need info that is immediately accessible, easy to understand- basic info- clear, simple communication</li> </ol>	Qual. 94% (I)
Ofteidal B et al., Journal of Advanced Nursing, 2010, Norway	Perceived support from healthcare practitioners among adults with type 2 diabetes	How adults with type 2 diabetes perceive support from HCPs and how it influences their motivation to self-manage their disease	Qualitative, (Descriptive/ explorative), semi-structured interviews with 3 moderated focus groups, 2 sessions, 4 hrs., taped and transcribed, analysis from Graneheim and Lundman, coded themes, n=19	<ol style="list-style-type: none"> <li>1. Empathic Approach - Need empathy- listening understanding, holistic approach</li> <li>2. Practical Advice and info- Need practical advice + info (can and cannot do) Need hands-on courses- diet etc. Need info related to everyday life</li> <li>3. Involvement in decision-making- Need HCPs being partners- HCPs experts on treatment and pts. experts on living w/ DM</li> <li>4. Accurate and individualised info- Need accurate, up-to date, individualised info, Not excess or inconsistent</li> <li>5. Ongoing support- Need support on continual basis, Need groups to share info</li> </ol>	Qual. 94% (I)

Author, Journal, Year, Country	Title	Objective	Method / design, participants (n)	Main results	Scientific quality
Wikblad K, Journal of Advanced Nursing, 1991, Sweden	Patient perspectives of diabetes care and education	How diabetic patients experience communication, what are their expectations and what knowledge does he need to manage his disease.	Qualitative, randomised groups for interviews (60-90 mins.), 4 groups, qualitative categories according to Marton, Larsson and Uljens, n=55	<p>Expectations:</p> <ol style="list-style-type: none"> <li>1. Continuity--same HCP</li> <li>2. Accessibility- continuous access to diabetes care</li> <li>3. Consideration- interest in individual person</li> <li>4. Support-contact when in doubt- QoL</li> <li>5. Responsibility- No need for "control" function from HCP</li> <li>6. Good medical skills-up-to date info from HCP</li> <li>7. Patient education- pt. need more information</li> </ol> <p>Needed knowledge:</p> <ol style="list-style-type: none"> <li>1. basic knowledge</li> <li>2. applicable to daily life</li> <li>3. Family knowledge</li> <li>4. Educational follow-ups- sustained knowledge</li> </ol>	Qual. 82% (I)
<p><b>Overall Results</b></p> <ul style="list-style-type: none"> <li>• Continuous- follow-ups, re-education, continuity, same HCP</li> <li>• Supportive- emotional support from family, friends, peer groups, HCPs, partners, no "controller", unique person, listened to, respected</li> <li>• Individual- adapted, flexible, tailored info</li> <li>• Specific - related to everyday life- diets, medication etc.</li> <li>• Reliable- Good medical skills from Info/HCPs- Up-to date, trustworthy, expert</li> <li>• Easily-Easy and immediate access to info /HCP</li> <li>• Multiple Formats -Clear, short, easy to understand, basic + additional, visual aids- graphs etc., internet, books, verbal or written</li> </ul>					