Self-care support in paediatric patients with type 1 diabetes: bridging the gap between patient education and health promotion? A review

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Abstract

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Background This study examines how the term ‘self-care’ imported from health promotion has been used in the context of patient education interventions for paediatric patients with type 1 diabetes.

Methods Thirty articles over the last decade were analysed, using a qualitative method of thematic coding and categorizing.

Results The term ‘self-care’ has been mainly used as a synonym for self-management of one’s condition and treatment. Indeed, the activities performed by paediatric patients independently or with the help of their parents under the term ‘self-care’ fail to explicitly take into account the general health and life dimensions of self-care, as defined in health promotion. Although such dimensions are implicitly present when it comes to define the parents’ and health-care providers’ roles in supporting the children’s emerging self-care capacity, their importance is acknowledged as a way of strengthening the children’s and their families’ capacity to respond to illness demands, rather than in relation to their general well-being.

Conclusion The discourse on self-care in the field of paediatric diabetes therefore appears to be oriented more towards disease and prevention, rather than health promotion. The psychosocial dimension of self-care should be particularly investigated, as young patients need to be supported in their efforts to gain autonomy not only in relation to the management of their condition, but in their lives in general.

Introduction

Type 1 diabetes is one the most frequent chronic diseases in children with an increasingly early onset (incidence doubled in 10 years in children under five).¹ Daily treatment of this disease comprises numerous tech-

nical skills (capillary glycaemia, multiple daily intracutaneous injections, urinary surveillance), which are often the shared responsibility of the children and their parents. The treatment affects various dimensions of the young patients’ lives and that of their families. It requires making decisions several times a day,

in particular with regard to certain complex health behaviours such as physical activity and nutrition management. Appropriate management of treatment is necessary to achieve good glycaemic control and to avoid long-term complications. Therefore, it is important that the children acquire autonomous behaviours. To help patients and families cope with the demands of chronic illness, self-management support has become a crucial component of the long-term medical follow-up of chronically ill patients.² Self-management support is one of the six areas of change suggested in the Chronic Care Model,³ to improve quality of care. In the field of diabetes, it is recommended that people with diabetes should receive diabetes self-management education and support according to national standards at the time their diabetes is diagnosed and as needed thereafter.⁴ Self-management support may take different forms, including patient education interventions.

The concept of self-management was coined for the first time in 1976 in the field of paediatrics, to define the responsibility that chronically ill children need to take over the daily management of their condition.⁵ Paediatric diabetic patients learn to develop autonomy in managing their disease within the everyday family life and this both in the independent carrying of techniques (behavioural autonomy) and in daily decision making (psychological autonomy⁶) to achieve optimal glycaemic control. Although this is of course extremely important, given the very serious consequences associated with failure to manage the disease and treatment, the aim of self-management does not sufficiently take into account the children's developmental, psychosocial and general health needs, whilst growing up with a chronic condition such as diabetes. Parental support plays an essential role in the children's process of developing autonomous behaviours⁷ and need to be adapted to the child's developmental needs according to their age. Reference may be made to Kieckhefer & Trahm's framework, to implement interventions aimed to support families with developmentally appropriate mile-

stones in their process of sharing responsibility over treatment-related issues.⁸

The concept of self-care seems to be a promising alternative to self-management, to guide patient education interventions in the field of paediatric diabetes. In the broader perspective of health promotion and general well-being, as opposed to narrow disease management and prevention, the concept of self-care was defined by Kickbush⁹ as integrating three dimensions: psychosocial life, general health and responses to illness demands. More precisely, self-care represents 'the range of behaviours undertaken by individuals to promote and restore their health' with a psychosocial dimension that is as important as the strictly medical dimension, to promote one's health.¹⁰

The concept of self-care originates in the 1970s, in a context of the people claiming self-determination with regard to and within the health system.¹¹ It was defined by Levin within a social theory that promotes participation and autonomy of each and everyone as a means of strengthening individual and community ownership of health. It also comes in a more general context of social transformation where individuals have increasing responsibility over their health.¹² Levin's theory defines self-care as an attribute of the lay people, whereby people increase their control over their health, independently of their health-care providers. An alternative use of the term 'self-care' emerged in the field of nursing in the 1980s, where self-care has been defined as the nurses' responsibility, as self-care agents, to increase people's capacity to self-manage their disease.¹³ Orem's theory of self-care acknowledges that patients need to address more than medical and health needs to take care of themselves. Yet, the operationalization of the concept according to Orem's definition is close to what has been described above as self-management supportive patient education interventions, with little emphasis on the patients' need for self-determination as they learn to self-manage their condition.¹⁴

This paper aims to examine the use that has been made of the term 'self-care' in the field of paediatric diabetes in relation to patient

education and to discuss possible implications for health promoting patient education practices. More precisely, this paper summarizes (i) how the concept of self-care has been defined in the context of patient education directed to children with type 1 diabetes, and (ii) which factors have been identified to influence self-care support in the same context.

Methods

Two databases – Medline and PsychInfo – were searched over the last decade using the following keywords: ('child' OR 'adolescent') AND 'self-care' AND ('patient education' OR 'health promotion') AND 'type 1 diabetes IDDM' (Insulin Dependent Diabetes Mellitus). The search resulted in the identification of 87 and 64 articles, respectively (thus a total of 151 articles). Of those, eighteen Medline articles were excluded because they either did not contain an abstract or were in a language other than English.

The abstracts of the remaining 133 references were screened by two independent reviewers (JP & CF). After screening the abstracts, 78

articles were excluded, because the term 'self-care' was not present in the abstract (77 articles) or because of a duplicate study (1 article).

Of the 55 remaining articles, one article was not available, leaving us with 54 articles for full-text screening. After screening the full text, 24 of the 54 remaining articles were further excluded, either because the word 'self-care' was not present in the text (18 articles) or because they did not specifically concern paediatric patients with type 1 diabetes (6 articles).

The final selection included 30 articles (Fig. 1): eighteen original research articles,^{15–32} five literature reviews^{33–37} and seven theoretical articles.^{38–44}

Information on both theoretical and practical aspects of self-care was extracted from each publication and analysed according to qualitative methods of thematic coding and categorizing.⁴⁵ The main categories of analysis had been predefined according to our research objectives: (i) references to theoretical frameworks to clarify the concept and (ii) identification and description of factors that influence practice within the patient-provider relationship. Our

Figure 1 Selection of the articles.

results are presented hereafter according to these two categories.

Results

How has the concept of self-care been defined in the context of patient education directed to children with type 1 diabetes?

A lack of explicit theoretical references

The term 'self-care' has been mostly used without explicit reference to health promotion. Two articles make reference to the theory of Orem,^{13,46} when they cite specific self-management problems arising in children or adolescents with type 1 diabetes.^{16,37}

Moreover, the term 'self-care' is hardly used on its own. It is used instead as a qualifier to other terms, such as *self-care* behaviours,^{17,18,24,34,38,43,44} *self-care* tasks,^{31,40} *self-care* activities,^{16,25} *self-care* practices,¹⁶ *self-care* attitudes,²⁹ *self-care* decisions,⁴¹ *self-care* strategy,⁴³ *self-care* management,^{16,37,44} *self-care* regimen^{18,42} and compliance with *self-care*.³⁷ It is sometimes used as well in relation to personal attributes,^{26,31,32,37} such as responsibility,³⁷ autonomy,^{31,32,37} independence³⁷ and well-being.²⁶

Self-care activities are mainly medically oriented

Although some authors in our selection of articles acknowledge the importance of the psychosocial dimension of health,^{17,21,29,31,37,38} by asserting that *self-care* activities contribute to the children's psychosocial adaptation, self-awareness, social comfort and meaningful interactions with their environment, *self-care* is defined by most authors as a set of disease-related activities. Indeed, most *self-care* activities are defined exclusively in relation to the physical dimension of health, and concern disease and treatment management: daily technical disease and treatment management such as insulin pump use,^{31,40} glycaemic control,^{15–19,25,29,30,33,38,42,43} insulin injection^{15,16,18,25,31,34,38,42}, daily IDDM management tasks,³⁸ foot care³³ or daily adjustment of the lifestyles with the disease and treatment: physical activity,^{16–19,25,30,31,33,38}

diet management,^{16,17,19,25,30,31,33,38,43} hypo–hyperglycaemia prevention,^{16,17,31,33} insulin dose adaptation.^{17,19,25,40,43}

Self-care activities are independent or shared activities

Self-care activities are activities that children conduct by themselves^{15–21,23–25,27–32,34,36–40} or with the help of their parents, if their capacities do not allow them to conduct them alone.^{22,35,41–43}

The respective roles and responsibilities of children and parents is an important aspect to be addressed in patient education activities, which aim to support the children's emerging autonomy towards their own health-care needs. However, when the child's autonomy is mentioned, it is usually understood as the level of independence in performing daily technical self-management tasks.^{31,32,37} The child's level of responsibility and autonomy in the decision-making process is mentioned by only three authors in our selection.^{16,37,39}

As a conclusion of the first part of our analysis, the concept of self-care – although widely used in the field of paediatric diabetes – is poorly defined in theory and appears to be more often understood in its narrow sense of 'taking care of one's own condition', rather than 'taking care of one-self'. The underlying definition of self-care is therefore close to what we have named 'self-management' in our introduction, with activities going back to only one of the three dimensions of self-care defined in health promotion,⁹ namely behavioural responses to illness. The other two dimensions, namely general health and life issues, are not explicitly addressed in the definitions retrieved from our selection of articles.

Which factors have been identified to influence self-care support in the context of patient education directed to children with type 1 diabetes?

This part of our analysis aims to clarify which factors have been identified to influence self-care, to support the children's growing autonomy and responsibility regarding their own

health needs. As already stated, the children's self-care responsibilities are shared and supported in the first place by their parental caregivers. We will therefore examine hereafter the parents' influence, before moving to the health-care providers' influence.

Factors which influence self-care support within the family

Several non-modifiable factors have been identified within the family, that might impact on the children's and adolescents' self-care abilities: the family structure,^{35,38} socio-economic status,^{37,38} ethnic origin³⁸ and history.⁴¹

However, most factors that impact on self-care within the family are modifiable cognitive and psychosocial factors and may therefore be supported by health-care providers through adequate patient (and family) education, as well as psychosocial counselling.

Cognitive factors. Parents' knowledge and awareness has been identified as an important predictor of parents' capacity to supervise their children's self-care activities. More specifically, parents are expected to (i) know about the disease and treatment, and in particular know how to adequately manipulate and handle complex technical procedures,^{15,38} (ii) understand their child's illness-experience²⁰ (iii) be aware of their child's own self-care capacities and level of autonomy.^{23,25,32}

Moreover, parents are expected to acquire pedagogical skills, to organize the process of sharing and transferring responsibility within the family.^{15,31,32,36}

Psychosocial factors. Alongside the cognitive factors, some psychosocial factors have been identified that are likely to impact on the type of self-care support the children receive within their family: the type of family functioning,^{34,35,38} the level of family stress,^{35,38} the existence of family conflicts,^{29,35,38,44} the type of communication between parents and children,^{16,35} the type of parental support.^{35,37,38}

Also mentioned are the style of parental authority,^{28,38,44} the level of parental

empowerment,²⁸ parents' responsibilities and role in society⁴⁰ and the mother's perceived self-efficacy regarding management of diabetes.³⁷

Self-care support interactions within the patient-provider relationship

In the paediatric setting, the patient-provider relationship is characterized by multiple relationships, as the child – until a certain age – is not met alone, but in the company of an adult caregiver, usually a parent. The multiplicity of interactions involved during a clinical encounter is well reflected in our selection of articles: interactions with the patient, with the family and with other health-care providers.

Interacting with paediatric patients. Health-care providers are expected to evaluate and support management of diabetes-related tasks,^{16,40} and supervise short- and long-term progress in managing the condition,⁴¹ whilst monitoring diabetes metabolic control.³⁵ Moreover, regarding the psychosocial challenges met by children who grow up with a chronic illness, health-care providers may help their young patients to cope with different life situations or social concerns (party, school, sport, eating, travel),^{15,18} and increase their satisfaction with the care received.^{20,28} This implies that health-care providers encourage the children to express themselves on various health topics other than diabetes¹⁷ show concern for the children as individuals and not only as patients¹⁶ and finally support the children's interactions with the health system, giving them an active role to play.²⁷ These findings are congruent with health promotion principles. However, few articles deal with this specific aspect of self-care.^{15–18,20,27,28}

Interacting with the parental caregivers of paediatric patients. Health-care providers should encourage parental involvement in the daily management of the child's condition.²⁸ Moreover, health-care providers may address the diabetes-related psychosocial challenges by: (i) working together with the parents on the

sharing of daily tasks, in relation to diabetes or general household chores,^{39,40,42} (ii) showing interest for family relationships and lifestyles^{16,19,43} and (iii) providing guidance and problem-solving support.^{18,35,41,42} Moreover, health-care providers should encourage expression of emotions linked to the illness experience within the family.⁴¹

Interacting with other health-care providers. The importance of the multidisciplinary health-care team has been stressed by several authors.^{35,38,43} Working in a multidisciplinary health-care team is an asset to support the development of the skills necessary to cope with the demands that a chronic condition puts on the children and their families.¹⁹

Discussion

Our review of the literature over the past decade highlights the current meanings given to the concept of self-care in patient education interventions for children or adolescents with type 1 diabetes.

We found that the term 'self-care' has been mainly used as a synonym for self-management of one's condition and treatment. As a result, the children's activities that are described under the term 'self-care' fail to explicitly take into account the general health and life dimensions that are present in Kickbuch's definition of self-care.⁹ Those dimensions are implicitly present when it comes to examining the parents' and health-care providers' influence in supporting the children's emerging self-care capacity. However, the importance of addressing the general health and life dimensions of self-care is stressed as a way of strengthening the child's and family's capacity to respond to illness demands, rather than as being important *per se*. This suggests that health-care providers tend to focus strictly on risk and disease prevention, and still fail to broaden their aim to more general health promotion. What seems to matter is to enhance adherence or compliance, as a way to ultimately promote well-being and quality of life, where well-being

is seen as a consequence rather than a factor of adherence.

At this stage of our discussion, we would like to acknowledge a limitation of our study, which has to do with our choice to focus exclusively on the term 'self-care' in the field of paediatric diabetes. As the semantic distinction between the comprehensive concept of self-care and the disease-specific concept of self-management is likely to be lost in most research articles reporting research on the management of type 1 diabetes, an extension of our research criteria to include articles on self-management as well, might have yielded other results. However, we believe that the results of our study on self-care illustrate well the difficulties and tensions currently encountered by most health-care providers in their clinical practice, as they try to move from a narrow focus on disease management, to a broader focus on people's health and psychosocial needs in relation to disease management.

These difficulties have been well described by Caraher,⁴⁷ following attempts to integrate health-promotion and health-care practices. Although health-care providers are willing to broaden the scope of their health-care practices, the central theme of the patient-provider interaction remains focused on disease and treatment. Through this attitude, the providers' expertise remains unchallenged. When psychosocial factors are taken into consideration, they are seen as possible determinants of improved or deteriorated health condition, rather than independent health promoting factors.^{48,49}

We hypothesize that the health-care providers' difficulty to embrace more systematically health promotion in their clinical practice might be linked to the current lack of evidence-informed models of interventions regarding the follow-up of general health and psychosocial needs of patients with chronic conditions.^{50,51} Although most health-care providers are aware of the complexity of their patients' needs, they are not well equipped to respond to these needs and therefore lack a sense of self-efficacy regarding the psychosocial dimension of their long-term follow-up respon-

sibilities.⁵² Moreover, whereas health promotion aims to be universally applicable across health conditions, patient education tends to be condition specific.⁴⁷ The model of health promotion is more complex, and therefore addresses the challenge of prevention more comprehensively than prevalent patient education models.⁵³ An alternative model has been proposed by Herbert, Visser and Green,⁵⁴ to integrate care, patient education and health promotion. According to their model of 'Clinical Health Promotion', health-care providers are expected to 'help people take greater control over the non-medical determinants of their own health'.⁵⁴ This definition is congruent with models of empowerment that go beyond self-efficacy and bodily control, thus aiming to support the patients' need for psychological autonomy and meaningful choices.^{6,55-57} According to the Ottawa Charter for Health Promotion, to make choices and participate in decisions is an important factor of well-being and health.⁵⁸

Conclusion

To support the emergence of autonomous activities to promote self-care in children and adolescents with type 1 diabetes, it is important to systematically ask the young patients what it means to take care of themselves, and what they actually do to take care of themselves. In doing so, special attention should be paid to what the patients (independently or with the help of their parents) do in the three dimensions of self-care that were defined in the perspective of health promotion.⁹ The psychosocial dimension should be particularly investigated, as young patients need to be supported in their efforts to gain autonomy not only in relation to the management of their condition, but in their general lives. To promote self-care in the perspective of health promotion means to focus on general well-being and quality of life because this is what matters to patients, and not only or predominantly because it is seen as a factor that might eventually contribute to better adherence. As

stressed by the Ottawa Charter for Health Promotion, health should be seen as 'a resource for everyday life and not the objective of living'.⁵⁸ As a conclusion of this literature review, we would like to argue for a more systematic implementation of health promotion in clinical settings, to support the patients' potential to become 'healthy ill people',⁵⁹ instead of only their capacity to self-manage their condition and treatment. This is particularly important in paediatric settings, where the patients' developmental and medical needs are closely intricated, thus requiring that patient education interventions more systematically integrate the principles and values of health promotion.⁵⁰

Conflict of interest

No conflicts of interest have been declared.

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