## **PSAD Special Issue Paper**

## Looking back on 25 years of the PSAD study group

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## **Abstract**

The year 2020 marks the 25th anniversary of the Psychosocial Aspects of Diabetes (PSAD) study group of the European Association for the Study of Diabetes. At the time, psychosocial diabetes research in Europe was steadily growing, but not well recognized. By establishing an official European Association for the Study of Diabetes study group, PSAD, for which purpose some hurdles had to be overcome, diabetes psychology became more visible and accessible to the scientific diabetes community. Over the years the PSAD study group has been successful in promoting the quality of research in the field through scientific meetings, mentoring, postgraduate education and publications. Looking back we can conclude that starting the PSAD study group signified an important moment in time, where researchers were joining forces to further the quality of the science, raise awareness of the importance of psychosocial aspects and promote the dissemination of psychological interventions in diabetes care.

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I vividly remember my first conference of the European Association for the Study of Diabetes (EASD), in 1991 in Dublin, by coincidence also my place of birth. Having worked with people with diabetes as a clinical psychologist for a number of years at the Diabetes Centre of the VU University Hospital in Amsterdam, I was hoping to meet colleagues at the conference with an interest in diabetes psychology and exchange research ideas. To my surprise and disappointment, there was very little attention in the scientific programme for behavioural research. I was fortunate enough to meet at least one colleague, Cathy Lloyd, a sociologist from the UK, who presented a poster on the Pittsburgh Epidemiology of Diabetes Complications Study. We fully agreed on the importance of psychosocial research in diabetes, but had difficulty finding other researchers from 'our field' at the conference. This was a sobering experience that fuelled my motivation to make a change, knowing that psychosocial research in diabetes was growing, although most publications came from the other side of the Atlantic. Behavioural diabetes research in the USA was clearly a step ahead of us in Europe, with Daniel Cox, Russ Glasgow, Mark Peyrot, Richard Rubin and Pat Lustman, among others, leading the field. But we were catching up in Europe, as illustrated by the publication in 1994 of the Handbook of

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Psychology and Diabetes, a guide to psychological measurement in diabetes research and practice, edited by Clare Bradley from the UK [1]. In that same year I published my own first diabetes-related paper in Diabetic Medicine, on the development and validation of the Diabetes Symptom Checklist for type 2 diabetes [2]. Much of the early work in diabetes psychology was focused on assessment, laying the foundation for integrating clinical tools for psychological screening and the evaluation of quality of life in people with diabetes. The field was growing, but not yet well recognized by diabetes professionals.

I had come to the conclusion that starting an international study group on the topic under the auspices of the EASD could be helpful in increasing visibility and recognition of psychological research. A study group could serve as a vehicle to facilitate international collaboration, further improving the quality and impact of the work.

As a first step, I informally approached the President of the EASD in 1994, at the time Sir George Alberti, to see if the EASD would be willing to support the idea. It was explained to me that the EASD was an association of individuals and if there was an interest in a new study group, it had to come from EASD members who could submit a proposal to the EASD board. Apparently, the EASD as a scientific organization had no view on the topic and there were no guarantees that this mission would succeed. The EASD Director, Victor Jörgens, allowed me half a 'purple page' in *Diabetologia* to advertise the idea of a psychology study group and have interested members contact me, which is exactly what

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happened; about 30 people responded, among whom were a few psychologists. We set up a meeting at the next EASD conference in Stockholm in 1995, which about 15 people attended and we formed an Executive Committee, with me as chair (psychologist, Netherlands), Axel Hirsch (psychologist, Germany) as vice-chair, Nuha Saleh-Statin (nurse specialist, Sweden) as Honorary Secretary, Margit van Doorn (psychologist, Netherlands) as Honorary Treasurer and John Day (medical doctor, UK) as Committee Member. We agreed on the name of the study group and the Psychosocial Aspects of Diabetes (PSAD) study group was born. The following months were used to organize a business meeting in Amsterdam to agree on the bylaws of the study group and plan further actions. The mission of the PSAD study group was: 1) to stimulate communication between researchers in the field of psychosocial aspects of diabetes; 2) to improve the quality of psychosocial research in diabetes; and 3) to stimulate the implementation of effective psychosocial interventions in diabetes care. Today this still is our mission [3].

It was decided to organize annual scientific spring meetings for which we fortunately were able to secure funding from a pharmaceutical company. The proposal to recognize the PSAD group as an EASD study group was formally submitted, but not immediately accepted. We were informed that some board members were not convinced of the need for this new study group. It was suggested that we join the Diabetes Education Study Group (DESG), established already in 1979 and consisting of a large group of medical doctors and nurses dedicated to the cause of patient education under the leadership of Jean-Philipe Assal [4]. After discussing our plans with the DESG executive committee and some EASD board members, our proposal was finally accepted and later ratified by the General Assembly in September 1997, at the occasion of the EASD/International Diabetes Federation conference in Helsinki. After 3 years, we were now officially endorsed as a study group. Meanwhile, we had been active in organizing scientific spring meetings, in Finland and Germany, that were well attended and highly appreciated, further strengthening our enthusiasm to make the PSAD study group a success.

As can be read from this historic account, there was no immediate enthusiasm, but rather some hesitation from the side of the EASD, which was by no means exceptional or specific to the board members of the EASD. Psychosocial research was unknown to many medical professionals working in diabetes. While it was recognized that psychological and social factors play an important role in diabetes management, only few diabetologists were familiar with psychological theory and methodology, and even fewer were actually collaborating with clinical psychologists.

Indeed, psychology in diabetes had come along way, from Menninger's speculations about a 'diabetic personality' in the 1930s [6] to the development of psychometrically sound questionnaires [7,8] and well-controlled studies looking at differences in neuro-behavioural disruption during

hypoglycaemia in type 1 diabetes in the 1990s [9]. The field was clearly moving forward [10], but not well recognized and here the PSAD study group could prove helpful.

This year marks the 25<sup>th</sup> anniversary of the PSAD study group's inaugural meeting in Stockholm. Looking back, I think we can conclude that the PSAD group has contributed both to raising awareness of the importance and opportunities of psychosocial research in diabetes, through symposia, postgraduate education, scientific publications and contributions to guidelines, as well as to further improving the quality and dissemination of behavioural diabetes research. The annual PSAD scientific spring meetings have been instrumental, offering a platform for scientific exchange and mentoring of young talents. We have seen a steady increase in scientific quality and well-designed interventions. The days of 'a shotgun approach which is conceptually fuzzy' are long gone [5].

The PSAD group has become family to me and it is gratifying to see PhD students who joined it years ago become leaders in the field of diabetes psychology, taking positions as professors at different universities in Europe. What started as a small group of enthusiasts has evolved into a multidisciplinary group of about 180 researchers from Europe, USA, Australia and South America, including psychologists, endocrinologists, nurses, diabetes educators, sociologists and epidemiologists, who have a common interest in the psychosocial issues of diabetes.

Within the PSAD study group three special interest groups are active: the European Depression in Diabetes group; the Children, Adolescent and Emerging Adults group; and the Patient Reported Outcomes group.

With this special issue of *Diabetic Medicine* we celebrate 25 years of PSAD and major advances in the field of psychosocial research in diabetes. It fills me with gratitude and pride to see that the PSAD study group is flourishing and I thank all who have contributed to making it a success. The journey continues.

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