

Diabetes Information Technology & WebWatch

Further User Comments Regarding Usage of an Interactive Educational Diabetes Simulator (AIDA)

ELDON D. LEHMANN, M.B. B.S., B.Sc.^{1,2}

ABSTRACT

This "Diabetes Information Technology & WebWatch" column continues the diabetes simulation theme from previous issues and overviews various user experience with the AIDA v4 interactive educational freeware diabetes simulator. AIDA is a diabetes computer program that permits the interactive simulation of plasma insulin and blood glucose (BG) profiles for educational, demonstration, and self-learning purposes. It has been made freely available, without charge, via the Web as a noncommercial contribution to continuing diabetes education. Since its Internet launch in 1996, over 145,000 visits have been logged at the AIDA Website—www.2aida.org—and over 29,000 copies of the program have been downloaded, free of charge. While these statistics may appear impressive, they do not tell the personal story of how people have been making use of the software, and what they actually think about the program. In this respect, this column documents some of the independent user comments about AIDA sent in spontaneously via electronic mail (email) by patients with diabetes and their relatives, as well as by health-care professionals. Comments posted to diabetes newsgroups and diabetes email lists, as well as a selection of those which have been found at other, linked, diabetes Websites are also highlighted.

INTRODUCTION

THERE IS GROWING INTEREST in the application of information technology in clinical diabetes care.¹ The rationale underlying this interest is the hope that computers may provide a way of improving the therapy offered to patients with diabetes, permitting more patients to be managed more intensively, in line with the experience of the Diabetes Control and Complications Trial (DCCT).² While database

systems and decision support prototypes³ often capture people's imagination as possible solutions for the future, one area of clinical diabetes care in which computers may have a great deal to offer is education.⁴⁻⁶ In this respect, education is an area where the use of information technology may provide a particularly powerful adjunct to currently available teaching tools.⁷

There are many different aspects to diabetes education, but clearly learning facts is only one

¹Academic Department of Radiology, St. Bartholomew's Hospital, and Department of Imaging, NHLI (Imperial College of Science, Technology and Medicine), Royal Brompton Hospital, London, United Kingdom.

²Dr. Lehmann is a co-developer of the AIDA diabetes simulator.

of these. The ability to gain experience is also of great importance. It is well recognised that it is not ideal for patients to learn about diabetes control solely from real life experiences because of the long time frames involved, aside from the possible very real dangers of hypo- or hyperglycemia. For this reason, it has been suggested that an interactive simulation of a diabetic patient might offer one solution.⁸ In the same way that aircraft pilots and air traffic controllers are trained on airplane and air traffic simulators, it should be possible for diabetic patients and health-care students to be trained to make appropriate responses to everyday situations on a diabetes simulator.⁹ While other interactive simulators of glucose-insulin interaction have been described in the literature,¹⁰⁻¹⁴ to date none of these have been distributed widely via the Internet, or widely applied.

AIDA v4 is a diabetes simulator that can be used for demonstration, teaching, and self-learning purposes to simulate the effects of changes in insulin therapy and diet on the blood glucose (BG) profile. The AIDA software can be downloaded without charge from the World Wide Web (www.2aida.org), where it is being made freely available, as a noncommercial contribution to continuing diabetes education. Since its Internet launch in 1996 over 145,000 people have visited the AIDA Website and over 29,000 copies of the program have been downloaded, *gratis*.

AIDA has been previously overviewed elsewhere in this journal.¹⁵ Briefly the program incorporates a compartmental model which describes glucose-insulin interaction in diabetes.^{16,17} The glucose model contains a single extracellular glucose compartment into which glucose enters via both intestinal absorption and hepatic glucose production. The insulin model contains separate compartments for plasma and "active" insulin,¹⁰ the latter being responsible for glycemic control while insulin is removed from the former by hepatic degradation.¹⁸ Examples of the sort of simulations that AIDA can offer can be found elsewhere in the literature,^{6,8,15} and on the Internet at www.2aida.org.⁷ Previous "Diabetes Information Technology & WebWatch" columns^{19,20} and other reports^{6,7} have documented various

user experience with the software. This current column reports some of the more recent comments received by electronic mail (e-mail) from users of the program, as well as highlighting various comments that have been posted to diabetes newsgroups and diabetes e-mail lists.

COMMENTS FROM PATIENTS WITH DIABETES AND THEIR RELATIVES

From Cambridge, UK: "Having used your AIDA 'toy' and gaining a more visual picture of the reactions between insulin diet and timing of meals I am finding the maintenance of my rather erratic control is improving. This erratic control has been the bane of my life from day one of diabetes (37 years ago). One doctor described my diabetic state as brittle but I believe that with the AIDA system I may have been able to sort out the problem earlier. I am pleased with the way I have been able to improve control. Yes I have been naughty in that I did experiment a little but having had years of experience I did so in a careful manner in conjunction with my GP [general practitioner] who sanctioned the alterations I wanted to try out."

From Florida, USA: "I was going strong with diet control for type 2 diabetes until I met polyalgia rheumatica and temporal arteritis which unfortunately require prednisone to control. The prednisone played havoc with my blood sugars so I had to learn about insulin. Fortunately I had practiced with injections for just such an eventuality and experimenting with AIDA helped too. Currently I take 4 injections a day. A basal comprising two shots 12 hours apart each comprising 8 units of Ultralente. Also 4 units of Humulin S at lunch and 14 units of Humulin S at dinner time. I find that I can simulate this regimen with AIDA, which has been a great help."

From London, UK: "Neat stimulation tool. I have learnt a great deal from using this."

From Wilton, Connecticut, USA: "I would like to offer my sincere congratulations to you in the development of your AIDA program. Several years ago I worked on a similar glucose modeling program. I can appreciate all too well the massive amount of effort that goes into cre-

ating and testing a valid model. . . . An area I see that would benefit in the future is a massive collection of blood glucose and insulin dosing test data available for analysis. I hope one day to be able to do enough analysis that with modeling like yours and enough patient specific data I could plot forward in time blood glucose in response to a patient's insulin dose decision. On a portable I would like to show a patient a 4–8 hour graph projection of the expected range of glucose over time. This would still not tell patients what dose to take, but would give an educated indication of potential for times of low or high blood glucoses in the next few hours. It looks like your collection of formulae has advanced the art closer to that day."

A relative of a diabetic patient from Dubai, United Arab Emirates: "Very useful for parents of newly diagnosed kids, thanks."

A relative of a diabetic patient from Histon, Cambridgeshire, UK: "My daughter was finally admitted to hospital to try and stabilise her diabetes. She has been all over the place for weeks now. In the last few weeks she has gone from blood glucose running above 20 mmol/L [360 mg/dL] on over 50 units of insulin, total for the day, to running below 3 mmol/L [54 mg/dL] most of the night on 9 units for the day. (Despite seemingly massive amounts of extra sugary food!). It certainly makes me think your caveats in AIDA may be 'heavy handed' if this sort of thing can happen despite being 'professionally advised'! It is difficult to imagine that anyone could get any more unstable by acting on suggestions from the AIDA simulations!:-)"

The father of a diabetic patient from The Netherlands: "I do not know who is behind the AIDA scene, but I would like to express my gratitude. About 6 weeks ago my son (age 14) was diagnosed with type 1 diabetes mellitus, just before our planned vacation. My wife and I spent all our vacation to learn about this deficiency and understand it, so we could maximize our help to our son. Thanks to the AIDA simulations, which I stumbled upon quite accidentally, we now understand the processes, and can understand why hypos and hypes happen. I am proud to say, that with your help I am a better guide than our wonderful and de-

voted diabetes physician. (Well, my advantage is that I know what my son ate!), and I now manage his diet and insulin intake, of course in good dialogue with the doctor. Who, by the way, when I showed her the AIDA graphs, became very interested (the first time she learned about your program)."

From Florence, Italy: "I am now retired and maintain some consultancies but I used to work for IBM here in Italy. During a visit to a customer in Rome, a friend of mine told me that his teenager son had suddenly developed diabetes and asked me to translate some lines from AIDA screens to better understand how to use it. While in IBM I used and taught about simulation for planning purposes and so I can appreciate the usefulness of getting to learn how a process works and the implications of changing a parameter without the damage that a true trial can do. I decided on translating the screens for my friend and I thought that with a little extra effort it could be offered to many more people if we could standardise and insert in the system the language selection option."

From San Francisco, USA: "I like the simulations a great deal. They are really useful. Thank you!"

From Portland, Oregon, USA: "I just wanted to congratulate you on the AIDA package and your, and your colleagues', efforts to promote it. . . . I do have some suggestions though. For those of us who aspire to tight control . . . one hopes we are the leading edge of the wave of the future . . . there are insufficient entry spaces for insulin, meals, and blood glucose measurements. It would also seem appropriate to add lispro insulin, despite its limitations—a drug of some value, and I would ask for IV [intravenous] insulin . . . possibly a wave of the future in the form of intraperitoneal insulin from implants. (In any case, it's an incredibly effective and safe way to take the stuff.) . . . Let me re-iterate though my appreciation of what you have put together; it is a marvelous education tool which I expect to see develop and be ever more widely used."

From an unspecified location: "AIDA has been both interesting and entertaining for me but unfortunately the stimulator will not accept my particular regimen. My a.m. injection includes 48 units of Humulin Isophane. This is

most disappointing but I have learned much from the programme nevertheless."

From the UK: "Keep up the good work—great Website."

From Canada: "As a diabetic I would like to say thanks for taking such an interest in all of us, you are very kind!"

From an unspecified location: "Just a brief note to let you know that I have downloaded AIDA—and find it a really neat program! Thanks:-)"

From France: "Naturally your software is popular owing to the dearth of 'upfront', 'usable' information on a subject that is 'life threatening' and that has existed for over 4,000 years without a cure but a plethora of treatments . . . Thank you for your help and a good piece of software."

From the USA: "Very nice Website, and very useful diabetes simulator."

While these comments are clearly from interested and motivated patients and their relatives, it is informative to see how positive they are about the AIDA simulator.

A relatively new addition to the AIDA Website has been the incorporation of a Guestbook (www.2aida.org/guestbook) in which visitors can leave short comments and messages. These have been received from people in many different countries and also have been very informative.

ENTRIES IN AIDA GUESTBOOK BY PATIENTS WITH DIABETES

From Jonesville, Louisiana, USA: "I am a type II diabetic diagnosed about 6 years ago. Last April, my 7-year old grandson went into diabetic ketoacidosis and nearly died. He is diagnosed as type I. When we brought him home from pediatric ICU [intensive care], he required 23–28 units of insulin per day and was almost impossible to control. The AIDA program has been a great help with establishing an insulin dosing schedule for him. Thank you for your work."

From the USA: "Neat Website. I really like the simulations. They are very useful, and educational."

From Republic, Ohio, USA: "I am interested

in learning a more refined way of controlling my diabetes. Hopefully, this will give me some ideas."

From Bozeman, Montana, USA: "I intend to give this to my diabetes educator. We're trying to get my BG levels lowered again. I'm on insulin now. Have been diagnosed diabetic for 10 years. I controlled by diet alone for 5 years, then pills and now insulin. I'd looked at this software many months ago and was impressed, but didn't download it at that time. My educator was unaware of its existence (until now)."

From Athens, Greece: "Thank you very much I find it very interesting and useful."

From the USA: "I will try to improve my health with your nice software. Thank you."

From Columbus, Ohio, USA: "Interested in working with a Windows-based version."

From Erode, India: "Simply a great Website."

From Kingwood, Texas, USA: "Hope the simulation is helpful, not as a doctor substitute, but to give me an idea as to how foods affect glucose levels."

From Neuquen, Argentina: "I want to use AIDA to improve diabetes control."

From Acambaro Gto., Mexico: "I think this is a very useful program . . ."

From the USA: "What a fun program!"

From Blumenau, Brazil: "I hope that the AIDA diabetes simulator can help me in my tests/research with diabetes, in Brazil. I will start to test the AIDA program today. (I am a 22-year-old diabetic)."

From Jacksonville, Florida, USA: "I am new to this program and trying to get some information about diabetes."

From Newcastle, Australia: "This is a neat site. Loads of good content, and easy to navigate. Please continue to make AIDA and AIDA online available for free."

From the USA: "Great Website:)"

From Cambridge, UK: "I have downloaded and used your simulator programme. I am a diabetic having a few problems with control at present and could not see an answer as I appeared to be chasing blood glucose readings. Having used this programme I can see where the problem lies and can now go to my GP to ask for advice as to the next step. I am also a researcher into IDDM [insulin-dependent dia-

betes mellitus] and feel certain I can find a 'professional' use for the programme."

In addition to these Guestbook entries, short comments have also been received by e-mail from AIDA users who are not necessarily patients with diabetes (they did not necessarily identify themselves).

SHORT COMMENTS FROM OTHER AIDA USERS

From an unspecified location: "I like the simulations a great deal. They are really useful. Thank you!"

From San Francisco, USA: "Very nice site, and very useful diabetes simulator."

From an unspecified location: "I really enjoyed the computer assisted instruction diabetes simulation software."

From the UK: "Still using the simulator with positive results. I think the visual impact helps with understanding as to the effects of diet, insulin and timing."

A program tester from Somerville, New Jersey, USA: "AIDA works fine under Windows XP. I was able to install on my Win XP computer and use the program, which I may add is very useful. Kudos to you and your colleagues for developing AIDA. You should have no problems with users utilizing AIDA on a Win XP computer."

A diabetes Website owner from the UK, highlighting how people might benefit from AIDA: "I am always interested in ways that we can increase interactivensess in the provision of diabetes educational material. Interaction means interest, interest means that people read more and remember more."

However, in addition to the above comments from people with diabetes and their relatives, and general AIDA users, it is equally illuminating to see how healthcare professionals have also found the software of interest/use.

COMMENTS FROM HEALTHCARE PROFESSIONALS/RESEARCHERS

A doctor from Wisconsin, USA: "I have really been talking up your AIDA program in our

system. I sent the link to all of our residents for them to review. . . . I also sent a note to our residency director. I am hoping to stir some interest in using this in some manner in the residency program. . . . I have been lecturing on diabetes. I presented your program online to a group of physicians and nurses at a conference last week. My topic was 'Diabetes Care in the 21st Century.' I demonstrated your program as one of the resources that are available to everyone to better educate themselves about diabetes. I received a lot of positive feedback about the lecture and the resources presented. . . . I will continue to look for ways to include AIDA in our health-delivery system. Please keep me posted as to your continued activity. You have a really good idea with this program."

A doctor from Helsinki, Finland: "Thank you very much for informing us about AIDA. Your software is excellent and you can be proud of your work!"

A doctor with diabetes from Sevenoaks, Kent, UK: "Is it possible for the AIDA model to account for the high glucose readings normally experienced some hours after the occurrence of a hypo? I appreciate this is a steady state model (and therefore probably not suitable for predicting transient effects) but I have never been able to work out what is the best course of action to take to avoid the high which usually follows a hypo, so any light you can throw on this would be rather useful. The model is clearly a very useful tool and will be yet more so (to me) when Humalog has been included. I also found the tutorial [www.2aida.org/tutorial] to be excellent in giving guidance on how best to achieve control."

A retired diabetes educator from Portland, Oregon, USA: "Once again, my congratulations on producing an immensely useful tool for training and inspiring confidence. Can I add a minor 'but' and also a more major one? For many, perhaps especially in this country (I speak as a retired educator), the initial clutter presents too many choices and is rather daunting. A simplified, more friendly presentation via a shell which invokes the same 'works' could encourage wider use, permitting migration as skill develops. The major 'but' concerns those of us who are tightly controlled, may our

tribe increase!, especially type 1s who often need to plan for the long term. . . . For us there is considerable advantage in using lispro (Humalog) insulin. . . . Could I put in a request that you consider adding lispro action curves to your repertoire? Thanks again."

A medical student from Rotterdam, The Netherlands: "Very good site. Helps me a lot by practising for my exams. I am a medical student and one of the high topics in our curriculum is the subject of diabetes. This is a great site to explore more about diabetes. I will further recommend it to my fellow students."

From Howrah, India: "I am an electrical engineer and at present working in the field of adaptive model reference control of an automated insulin dispenser system. I have been very much helped by your published works. I am also using your AIDA software to ascertain different patient conditions."

From Norfolk, UK: "Having toyed with the simulator some more I have found it is accurate in indicating the blood glucose trends when various actions have been taken. I have used blood glucose results from some of the case studies I have. I have found that the predicted results are close to the actual results experienced by IDDM's [patients with insulin-dependent diabetes mellitus] in their daily lives. . . . At a private level I have shown the simulator to a young diabetic (aged 14) who has been playing with diabetes in the way the simulator can be used (missing injections, meals or over eating etc), to the person's mother's joy he has decided not to experiment with his diabetes any more but to play with the simulator instead! I believe that AIDA could be used with young diabetics to illustrate the dangers of not taking care of their diabetic control. This may also have a role to play in educating newly diagnosed diabetics in the importance of taking control and not being afraid to adjust their own insulin with guidance from their doctors."

All the above comments illustrate the many and varied ways in which people from different 'walks of life' and backgrounds, from different countries, have been making use of AIDA. However, in addition to these spontaneous comments received by e-mail, it is also interesting to see what people have written

about AIDA in public diabetes newsgroups on the Internet.

POSTINGS TO DIABETES NEWSGROUPS

Posted to Diabetes World Newsletter by someone with diabetes: "Can't remember if I mentioned before that the final new 4.3 version of AIDA is now available at the new AIDA web site: www.2aida.org AIDA is a free downloadable program for seeing how changes in insulin regimens will affect your BG levels. It's fun to play with, even if you don't use insulin, as it shows how various factors affect your control. And the price is right <grin>!" [i.e., free].

Posted to diabetes newsletter by an endocrinologist: "Want to have some fun? Want to do some simulations of various insulin situations? It isn't really treatment but you might even get some different ideas on how you might handle things! AIDA diabetes software simulator—www.2aida.org Have a good time!"

Posted to alt.support.diabetes.kids Usenet newsgroup: "re: Freeware AIDA diabetes software. This is a very useful tool. I recommend anyone who is having or has had problems with their control to try this software out. Thank you to the program's developers."

Posted to alt.support.diabetes Usenet newsgroup by someone with diabetes: "Re: I'm overdoing my bedtime snack . . . I'm concerned about having a hypo when I am sleeping, so I have been overeating carbohydrates at bedtime. Hypos come on so fast during the day, I don't know if I would be woken up by one. It makes sleeping scary. I tested in the middle of the night for the first time last night, I got up three times to test, and I was high all night."

Response posted to alt.support.diabetes Usenet newsgroup by someone else with diabetes: "Starting insulin is scary, especially when you get a lot of hypos. . . . are you taking NPH and Regular or Humalog insulin? You need to do a bit of work to find your basal needs and your bolus (units per carb[ohydrate] ratio) insulin. . . . I personally prefer Ultralente as it provides me with my basal insulin more purely than NPH does. . . . NPH has a meal component in it so you need to look at your

low periods and when they coincide with the activity of your insulin. . . . The AIDA site (www.2aida.org) has a good insulin simulator to show you when your insulin is peaking."

Posted to alt.support.diabetes Usenet newsgroup: "Re: Use of AIDA for simulating insulin pump regimens. Get AIDA at www.2aida.org/. I grant it's limited for pumpers, but it can be done. And the insights gained are invaluable."

Follow-up posting to alt.support.diabetes Usenet newsgroup regarding how to set up an insulin pump simulation using AIDA: "Make two entries for your basal dose using Ultralente and a 12 hour separation. Try to share one of these Ultralente entry times with a real meal (i.e., bolus). That will permit you to do 3 boluses in one of your tracking days (using AIDA). For example, when last pumping, my basal was 8.0 units/day. So with AIDA, I'd enter 3 units of Ultralente in the a.m. and 5 units of Ultralente in the p.m. This gives a background curve that is slightly elevated in the morning, which (to the best of my knowledge) is fairly typical for those (like me) who don't have much of a BG rise in the morning. If you do have a big morning blood glucose rise (a.k.a. 'dawn phenomenon'), then use a slightly more lopsided ratio—for my 8 units I'd go to 2 and 6 as the most extreme (i.e., peaky) choice for your basal background. Don't do [1/7] units because you need some a.m. Ultralente to help flatten the basal curve in the afternoon." [More information about simulating possible basic insulin pump regimens using AIDA and AIDA online can be found at www.2aida.org/pump on the Web.]

Posted at alt.food.diabetic Usenet newsgroup from New Zealand: "For some completely free diabetes software, people might like to check out www.2aida.org The software deals with glucose and injecting insulin."

Message sent independently as a press release to U.S. newspapers by an AIDA user from Florida, USA: "Good Day, I am sending information about this program and the Website www.2aida.org in the hope of your getting this message to all concerned. As a parent of a teenage diabetic I know that other diabetics and their loved ones will benefit greatly after using the AIDA program. AIDA has been written for diabetics and is free. Thank you" [sent together

with background information about AIDA from the AIDA Website].

Posted to alt.support.diabetes Usenet newsgroup from the UK: ". . . having used AIDA it really is a jolly useful educational tool and in this case I have to endorse it. Remember, it is a mathematical simulation and, apart from its ugly DOS look-and-feel, it is very helpful."

In addition to these newsgroups, one of the most active Usenet newsgroups on the Internet is the misc.health.diabetes newsgroup. This is often the first diabetes newsgroup that people new to the Internet will discover, and it has the greatest amount of traffic/postings, so it is interesting to see what people have written there about AIDA.

POSTINGS TO misc.health.diabetes USENET NEWSGROUP

Posting: "The AIDA software is the best software I have found for the technically oriented diabetic. It is based on solid scientific data and has a lot of data on insulin actions. Observe the caveats that they publish and patiently play with it. All diabetics don't wear the same sized shoes and AIDA is not intended to fit an individual but is a good guide line to further your understanding of the insulin-food actions. I use pencil and paper for daily records. I use this software to do 'what if' runs. I always ask, why wasn't something like this done in the USA long ago. We have invested enough money in one way or the other."

Posting by someone with diabetes: "I'm having a bit of difficulty with Ultralente at the moment: I seem to have too much basal from around 2pm to around 8am, but 8am to 2pm, too little . . . recommendations would be welcome! (I've tried my doctor—he says 'come back in 3 months, and see if the pattern changes'). I don't like this pattern . . ."

Reply posted by someone else: ". . . I did not see the original post. But the above fragment indicates she might benefit from the AIDA Type 1 diabetes simulator, free software which has just been updated and placed on the Web for download. This is a DOS program (which also runs in a DOS window in Win 3.1+ and under SoftWindows with a Mac) that allows

the user to graph changes in control patterns by adjusting the amounts and timings of food (in grams of carbohydrate) and insulin (of all types except Humalog). It is particularly useful in showing the pattern of intermediate-acting insulins such as NPH & Lente, as well as Ultralente. (There is a caveat that the user regard the graphing as a 'simulation' and not a guarantee of real-life results. In other words, your mileage may vary.)"

Exchange of comments posted: "The main problem I have with AIDA is simply what it's not: it's a program to show you the different effects of different insulins, it's not a program to allow you to build a model of your own insulin use, which would allow you to try some radical solutions without endangering your body (e.g., a shift from 50%/50% basal/bolus to 20%/80%)."

Response posted from South Pasadena, California, USA from a patient with diabetes: "Well you can simulate this example with AIDA—and it will show you the general sort of thing that might happen to the BG profile with such a change."

Posted reply: "But it is said again and again on the site that we shouldn't use AIDA to simulate such a thing."

Further response posted from South Pasadena, California, USA from someone with diabetes: "I think the British expression is 'Nudge, nudge, wink, wink' (courtesy of Monty Python). The cautionary statement is there both to avoid legal hassles and/or to prevent an unknowledgeable diabetic from acting rashly on AIDA's modeling. It goes without saying that every diabetic is different. But that doesn't prevent you from using it to see the POSSIBLE, indeed LIKELY effects of a change in insulin therapy. In other words, the primary purpose is educational, not therapeutic. On that basis I find AIDA extremely useful."

Another posted response: "Actually you CAN use AIDA to build a model of your own insulin use, despite the program clearly and repeatedly cautioning not to use it as a guide for actual changes. (The authors would not want to be held responsible if you should happen to overdose yourself into the hospital.) AIDA does show you what is LIKELY to happen by switching to a different insulin—or changing

your carbohydrate consumption, dosing pattern, etc. You can also mentally adjust the graphing to emulate Humalog, even though that is not built into the program, because you are quite familiar with how Humalog works. It's more typically the basal insulins which give the most trouble. In other words, it can help you spot the big picture. But I agree this presents something of a conundrum: In order to gauge AIDA's modeling effects on you, you need to know how you vary from the norms which are built in to the insulin profiles. In other words, you already have to know a lot about insulin self-management. People who are just starting insulin, and for whom learning the best therapy is more urgently important, should not use the program without professional medical guidance. So perhaps the best use of this program is in an endocrinologist's office."

Posting from a software developer: "I am developing diabetes software for Win98–95 and NT. I have an insulin blender utility that allow the use of up to 3 insulins in one injection. I would like to graph the combined insulin's Activity Profile. What I need is access to the data that was used to create the Insulin Activity charts like the graphs that diabetes companies have at their Websites. I have searched the Web and e-mailed various diabetes companies, but I have had no luck coming up with the statistical data that I need to formulate the algorithm for combinations of insulins."

Posted reply: "I was able to extract insulin data from the AIDA software. . . . It is the best data I could find. Most data I found was garbage and just plain wrong. I extracted the AIDA data by setting up scenarios and manually recording the data from the program displays."

Posting: "The best source of insulin data is the AIDA software. If you use the scenarios they have in this software, the data is presented in digital form and it is easy to get good values. It takes a little work to set up a case where the parameters are separated. The curves seem close to reality if you set up an appropriate case. This program has been of great value to myself. Most of the curves I found on the Web were vague replicas, to prevent problems with misuse. I looked at all possible sources about

three years ago. AIDA was the only good source. But you have to do some intelligent work to extract the insulin data."

Posting: "If I were to get data with times, blood sugars and insulin taken, I could use that as input to an artificial intelligence piece of software to tell the user or the pump itself how much insulin to give. The training of a neural network requires a lot of sample data, the more data, the better training the neural net would receive."

Posted reply: "There is information about a diabetes simulation program, AIDA v4, at www.2aida.org together with a lot of theory (involving physiological 'compartments' and differential equations), together with data for about forty 'case' studies. You can plug in different insulins and dietary changes, and see a graph showing the results before and after. There is a strong warning that individuals vary too much for it to be used for planning treatment changes. It is being used as an educational aid. I would like to see a version to cover type 2 diabetes. One of the research uses of the program is to generate reasonable looking blood glucose measurements for input to other computer programs."

Posting regarding insulin activity curves: "The diabetes company insulin curves are only for vague generalities. It is more than they would give me years ago when I requested info. The best data for insulin is extracted from the AIDA program. It reads out digital values if you set it up correctly. Their data best fits my personal measurements. I have done a lot of work in integrating the curves and getting data such as insulin remaining and insulin used. These proved useful to me. The final data fitted reality very closely."

Posting: "A couple of months ago I purchased the XXXXXXXXXXXXX software. I evaluated this package and decided it was of little value to me. I am still looking for software for insulin dose info."

Posted reply: "I just saw your posting earlier today. If you will check the FAQs [Frequently Asked Questions] posted in this newsgroup under Software, you will find information on how to download for free the AIDA software (for DOS/Windows) that can be used to plot insulin dosages."

Posting: "I have followed diabetic software, investing money to examine various packages. The only one I consider worthwhile is the U.K. Program 'AIDA.' It is free and has technical data worth reading."

Posting: "The best software I know for 'insulin dose info' is called AIDA, a free DOS/Windows program. Although it warns you clearly that you should not alter your insulin doses and times without medical supervision, the program allows you to enter all your personal parameters, then to enter insulin doses and times (for all insulins except Humalog/Lispro) and graph the projected results to the screen. This program is not for beginners to insulin therapy, but it is extremely configurable; it may therefore serve your needs. The download sites are listed in the newsgroup software FAQ, which is posted every few weeks."

Posted by someone with diabetes: "I am a totally frustrated diabetic. I have been diabetic for 12 years. Here is my problem: Does anyone out there use ultralente? If so, what is the best time to take it in order to get good morning numbers. Per my Doctor, I started taking it at 10:30 pm but would wake up with high numbers? Then he changed me to 8:30 pm which didn't change anything. I wonder if I should take it along with my Humalog at dinner time. I am totally frustrated!!!!!! All I want is good control and I can't seem to get it."

Response posted by someone else with diabetes: "You might try downloading the free DOS/Windows computer program AIDA. It will allow you to enter different dosages and times of virtually any type of insulin (except Humalog/Lispro), then graph the projected results. This will then give you some ideas on what to try. The program can be downloaded off the Web at several sites mentioned in the software FAQ."

Posted from the USA, by someone with diabetes: "I have used the AIDA site many times and found it very useful. I found the first reliable insulin activity data there. I found some good technical descriptions of the technical aspect of diabetes. I am still using some of the data I was able to extract as numerical data from the simulation runs. I can see that it presents a problem for some people. My back-

ground is very technical and I like the approach. . . . It is good free software. But not for everyone. I will take a look again, to be sure. Some people prefer Dr. Bernstein [low carbohydrate diet and exercise programme to optimise glycemic control], I prefer the AIDA site. It depends where you are coming from."

Posting from a newly diagnosed diabetic: "I'm just finishing my 1st week on insulin. I'm gradually feeling better but wondering—I get the impression that most people who are using insulin do so in a more complicated way. That is: more injections, mixing types, etc. I realize this gives you better control. Does anybody just do the intermediate acting N (or NPH) insulin on its own? It would indeed be interesting to learn if anyone out there has had sustained success (i.e., tight control) using just NPH."

Reply posted by a relative of a diabetic: "My mother was on NPH alone (one injection daily, upon waking) from December 1988 until April 1995. She ate spoiled chicken salad at a restaurant, was very sick for one night (vomiting $\times 12$), and ended up in the hospital to get her blood glucose under control (blood glucose at admission was over 700 mg/dL [38.9 mmol/L]). She'd been ranging from lows up to highs of 240 mg/dL [13.3 mmol/L], but most days she was between 45 mg/dL [2.5 mmol/L] and 150 mg/dL [8.3 mmol/L]. Her doctor put her on 70/30 Humulin (that's 30/70 in Britain, where they state the % of regular insulin first), 30 units upon waking, 14 units just before dinner. Apparently, this was a good time to put her on something to give her better control. Anyway, she did very well until that episode of nausea and vomiting at keeping fair control using just one injection of NPH daily. My explorations with AIDA (the best software available for learning the ebbs and flows of blood glucose) indicate she would be better served by splitting the dinner dosage into its NPH and regular parts, and taking the NPH about 10 p.m., and the regular prior to dinner. This controls that morning high much better, in the simulation. AIDA is not perfect, and should not be used as a treatment indicator, but it does help one come up with ideas for things to try, while working with one's physician."

Posting: "I gather you've used AIDA and find it useful? I've just given it a try this past 2

days and am getting some useful insights from it. Any pumpers using it? . . . At first I thought not having an accurate match with the insulin curve would be a limiting factor but am now not finding it to be a problem. I do think it helps if you're a techie <smiling>. Any non-technie's who've jumped in and used it?"

Posted reply: "I have used the AIDA program for several years. I also use spread sheets to study the combinations of insulin and to do 'amount used up and remainder of past dose.' It has contributed a lot of info for me . . . Several people have tried the AIDA program and found they were not prepared for the technical aspects. The supporting documentation was useful for me. Too technical for some people. The insulin curves in the program seem to fit my experience better than many of the 'paint brush' types in U.S. publications."

Other posted response: "I tried the on-line version and found the lack of pump support was hard to work around. I'd like to see more direct support for pump protocols. However I found the graphs *very* nice. I think the models they use can provide a lot of insight. Great stuff . . ."

Follow-up posted response: "Try making 2 insulin entries using Ultralente spaced 12 hours apart. When last pumping I was using a basal dose of 8 units, so I'd use 3 units in the a.m. and 5 units in the p.m. The graph I get from these amounts/timing is similar to what I was doing with my pump basal."

Posting: "Up until five years I was unable to find any good insulin activity curves. There are some junk curves still around. My first good data was derived from the AIDA program. At one time a diabetes company refused to supply data because of legal reasons and individual differences. The activity curves are complex and cannot be reduced to simple linear explanations. The decay is a function where a certain per cent of the remaining insulin is released per time period. The activity time is a matter of definition. I use the activity curves and time integral curves and charts to adjust my dose. I am able to account for overlap in doses, etc. Due to individual differences and the effort in use of activity curves it may be too much work to engage in except for the technical type."

Posting from someone with diabetes: "I noted a posting that was critical of a posting for free software. This is not a spam but an excellent tool for the diabetic, especially the technically oriented person. It is the only decent program I have found. I paid about \$70 for a spammed software posting. This was several years ago. It was a very crude program and useless. The AIDA program has an excellent technical description of the techniques used in the program. It is far ahead of anything I have seen in the US. I have had the program for several years and have never been solicited for anything except suggestions on how to improve the program. I thank the developers for a fine piece of work. Now if the U.S. organizations could get away from the games long enough to produce similar software I would be delighted."

Posted by an AIDA user from West Point, Virginia, USA: "I have tried the AIDA Simulator software and SO FAR what my doctor suggested that I do, the software has BACKED him up. Incidentally there are more than enough statements in the software telling everyone who uses it that it is for training only."

Posting: "Re: Free diabetes software. Try the AIDA simulator program . . . great way to get a handle on your insulin activity curves . . . no money exchanged . . . purely to help diabetics."

As the AIDA diabetes simulation approach has become more widely known about, Internet users have started setting up links from their own diabetes Web sites to the AIDA site (www.2aida.org). It has been informative to read what is written with some of these links.

DIABETES WEB SITE LINKS

Independent software review posted on the Web: "AIDA is 'a diabetes software simulator/modeling program of glucose-insulin action + insulin dose and diet adjustment in diabetes mellitus for education, self-learning & teaching diabetes programs.' It can be used as an 'educational toy' for modeling by insulin dependent patients and offers a fascinating array of general information, sample cases, and room for you to add your own data (as long as you don't start treating yourself). It presents data

through a number of graphs and charts and offers 'advice' based on the data you have entered about yourself. The authors point out in the strongest way that: 'AIDA is *not* intended for individual patient blood glucose prediction, individual patient diabetes management or therapy planning. AIDA *cannot* generate individual patient therapeutic advice. It is a condition of use that AIDA must *not* be used for therapy planning.' . . . The interface is pure DOS (the install program requires Win9x/ME) and, unless you are used to working in a text-based operating system like DOS, you may find it a little strange at first. We were particularly impressed with the various levels of information, most of which aren't apparent until you really start to use the program. For anyone who is an insulin-dependent diabetic, AIDA is a wonderful tool. It does not substitute for visiting your doctor, but it does show the results of various simplified scenarios which could help you to better manage your condition."

Website link: "AIDA, Diabetes analysis and training software. This link takes you to an interesting site that contains a new simulation tool for analysing one day or average day program of a user of insulin. Insulin intake and meals are included as well as blood sugar readings from one's own meter. An educational simulator of insulin and dietary adjustment in insulin-dependent diabetes mellitus (IDDM)."

Website link: "Training games and simulations . . . Links to evaluated sites. This Business & Industry group evaluated a number of sites in an effort to assemble a list of some of the best internet sites that provide training resources. These sites offer product media ranging from CD-ROM and electronic applications, board games, text-based and combination training activities. What we found is a wide variety of environments using games and simulations for training purposes."—"AIDA: www.2aida.org—AIDA is very text heavy but very organized. There is a tutorial, a demo and a simulation to help the audience understand the technical information. This site contained a freeware educational simulator program of glucose-insulin interaction and insulin dosage and dietary adjustment in diabetics. The information is targeted to both medical professionals and patients. Score: Good+."

LENGTHY REVIEW/POSTING TO A DIABETES NEWSLETTER/ARCHIVED WEB SITE LINK

Website Worth Visiting

Two years ago we reviewed a novel diabetes Website that we thought well worth visiting. At the time we wrote: "This program is a wonderful VISUAL component in letting a newly diagnosed insulin user 'see' what is happening and how it is happening, and how the insulin HELPS their condition become treatable and livable," says one AIDA user. "Diabetes doesn't have to be thought of as a death sentence. With the right information, and the correct way of presenting it, anyone can understand it."

Well that is what we said then. AIDA online and the AIDA downloadable software have recently moved to a new, dedicated facility (www.2aida.org). What's new since we last reviewed these diabetes simulators? Well, AIDA v4.3 has been released and can now be downloaded for free from www.2aida.org

This upgrade offers glycosylated hemoglobin (HbA_{1c}) estimates for the blood glucose simulations. Therefore assuming the simulated blood glucose control was maintained for a 2–3-month period, users can get an indication of what the HbA_{1c} level might be. AIDA v4.3 also provides a new case scenario import/export facility which allows cases to be transferred between users/computers via e-mail/the Internet. The intention is that over time this should permit a larger database of interesting case scenarios to be compiled for free downloading from www.2aida.org

Technical upgrades with the move to AIDA v4.3 include a streamlined installation procedure for Windows users, a 'fix' for AIDA usage on fast Pentium II/III PCs, hotkey by-passing of introductory caveat screens (much requested!), and a reduced file download size (1.0 Mb instead of 1.5 Mb) so the download will be faster and the install file will now fit on a single floppy diskette.

Also to keep people informed about future upgrades to AIDA—including the launch of 'AIDA for Windows'—a new, automated AIDA registration/announcement list has been set up. To subscribe to this very low volume list, users simply need to send a blank email note to subscribe@2aida.org

In addition to all this, AIDA online has been integrated in with the main AIDA Website and can now be accessed directly at www.2aida.org/online. This new Web-based simulation facility runs on a faster server and makes use of smaller graphics/simulation files than before, thereby potentially reducing the online simulation times. Furthermore there are a whole series of articles about the use of computers in diabetes care which are freely available at the Website. These can be accessed directly at www.2aida.org/articles

So for a fun Website—with some very useful, free diabetes content—why not pay www.2aida.org a visit!

DISCUSSION

These AIDA users have all clearly derived some benefit from experimenting with the diabetes simulator. However, the above feedback also offers some more general insight into why people with diabetes and their relatives may be turning to the Internet to gain knowledge, as well as highlighting the sort of information and diabetes guidance that may be exchanged between patients (and relatives) in diabetes newsgroups and chatrooms.

Interestingly the comments documented above largely mirror those of independent healthcare professionals, and patients and their relatives, which can be found elsewhere in the literature,^{6,7,19,20} as well as on the Web (www.2aida.org/reviews). However, while intuitively the benefits of such an interactive educational diabetes simulation approach may seem self-evident, it is acknowledged that formal evaluation studies are still required, as for any other medical intervention, to demonstrate a definite clinical utility for the use of such software.²⁰ In this respect, Figure 1 highlights the

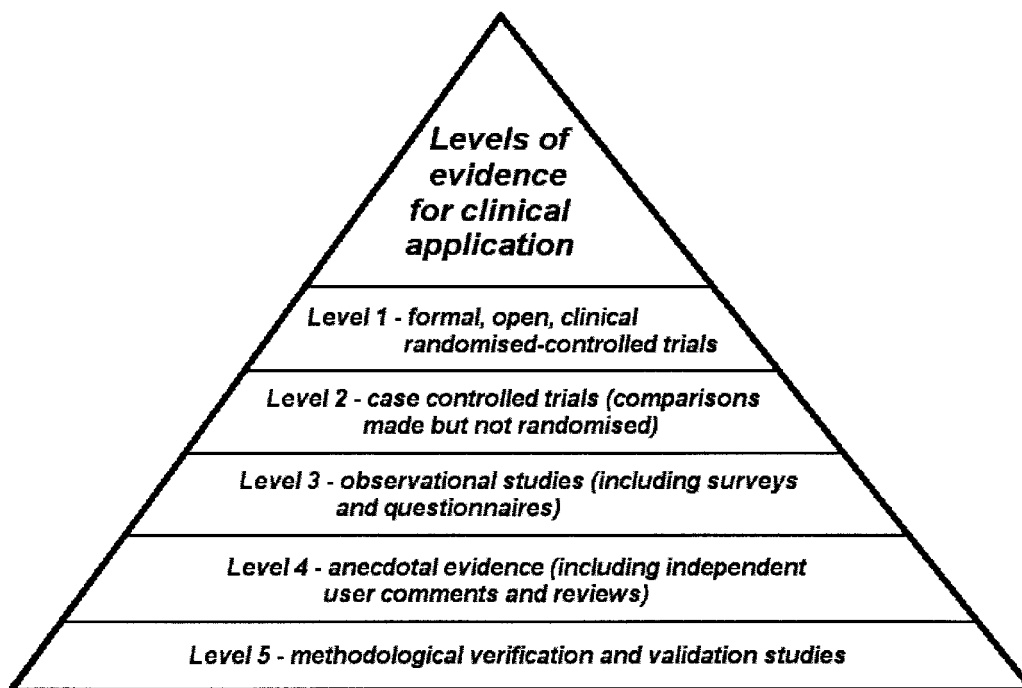


FIG. 1. A pyramid of different levels of evidence for formally evaluating educational/clinical use of a piece of software that can be applied to a program like AIDA (derived from Lehmann²¹).

different levels of evidence that may be sought for evaluating the educational/clinical use of a piece of software, like AIDA.²¹

Level 1 studies (randomized controlled trials [RCTs]) are clearly the gold standard method for rigorously assessing educational/clinical utility. Nevertheless, useful information can also be obtained from less formal studies, and in many cases, these can be easier to undertake and involve more subjects than RCTs.

In the case of AIDA, under level 5 (methodological verification and validation studies), a quantitative assessment was reported in 1994 to document the accuracy of the blood glucose simulations in a cohort of 30 patients with diabetes.²² While the simulations were shown to be unsuitable for individual patient glycemic prediction and therapy planning, they have found widespread use for educational/demonstration/self-learning purposes where individual predictive accuracy is less critical.^{23,24}

Using the evaluation scheme shown in Figure 1, the current report would fit under level 4 (anecdotal evidence including user comments and reviews). While this feedback has been very encouraging, the next stage in the evaluation process is clearly to undertake level 3 ob-

servational studies (including the use of surveys and more formal questionnaires²¹) and prospective RCTs.

For RCT use, a standardized protocol for the evaluation of such diabetes simulation programs has been developed,^{25,26} and early pilot study (preliminary) results from a small number of patients ($n = 24$) have shown this to be a viable method for formally evaluating programs like AIDA.²⁷ However, a large number of subjects in multiple centers are clearly required to properly test out the use of this approach as a teaching tool.

Nevertheless, a wide range of users in many different parts of the world do seem to have identified AIDA as an accessible source of information about glucose-insulin interaction, and a useful supporting method for diabetes education. Taken together with the growing number of reports of user experience,^{6,7,19,20,28,29} collectively these comments highlight the potential for empowerment that some people feel can result from use of the program. Given this, it is suggested that the experience with this approach is sufficiently encouraging to warrant more formal, randomised controlled clinical studies to identify the actual

clinical/educational role for such interactive diabetes simulators.

SYSTEM AVAILABILITY

The latest release of AIDA (v4.3a) can be downloaded, without charge, from www.2aida.org on the Internet. The program runs on IBM PC or compatible 80386/80486/Pentium-based machines and requires approximately 3 Mb of hard disk storage space. The software can also be used on Apple Macintosh computers running PC emulators such as Virtual PC or SoftWindows. A fully Internet-based version of AIDA, called AIDA online, is also available for use free-of-charge at www.2aida.org/online on the Web. This allows AIDA's diabetes simulations to be run from any computer, anywhere, provided it has an Internet connection and a graphical display.

An interactive educational Diabetes/Insulin Tutorial that has been integrated with AIDA online can also be accessed without charge at www.2aida.org/tutorial on the Web. This allows visitors to dynamically simulate some of what they have learnt in the tutorial about balancing insulin and diet in diabetes, using AIDA online.

People who wish to be automatically informed about future updates and enhancements to the AIDA/AIDA online diabetes software range can subscribe (for free) to the AIDA diabetes simulator announcement list by sending a blank email note to subscribe@2aida.org

Any readers who might be interested in collaborating by teaching in their clinics using AIDA or by applying a standardised randomised controlled trial protocol^{25,26} in an evaluation of AIDA in clinician, specialist nurse or educator-led patient teaching sessions are invited to contact the author. Further information about the evaluation of AIDA for patient use can be found at www.2aida.org/evaluate on the Web.

FURTHER TOPICS

If you would like to suggest further topics or Web sites for future "Diabetes Information

Technology & WebWatch" columns, please e-mail information—with a brief description of the site/suggestion to Dr. E.D. Lehmann: info-www@2aida.org (please write Diabetes WebWatch in the subject line). You can also fax information to (503) 218-0828, quoting "Diabetes Information Technology & WebWatch."

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Address reprint requests to:

*Dr. Eldon D. Lehmann
Academic Department of Radiology
St. Bartholomew's Hospital
London, EC1A 7BE, U.K.*

E-mail: info-www@2aida.org

Web: <http://www.2aida.org/lehmann>