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Shared decision-making and patient decision aids in dermatology

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Conflict declarations:

Jerry Tan holds the copyright for "What can you do to manage your psoriasis? A decision aid for plaque psoriasis patients."

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What this adds:

- Shared decision making combines individual patient interests and values, and clinical best evidence under the guiding principle of patient autonomy.
- Patient decision aids support shared decision making and facilitate decisions that have multiple options with varying outcomes for which patients may attribute different values.
- Patient decision aids may provide accurate information on disease and treatment, establish the need for a decision, encourage deliberation of choices, clarify patient values and elicit preferences.

Patients are experts in their illness - they directly experience symptoms and psychosocial impact within the context of their personal circumstances. Health care providers are experts in management of disease with access to medical information and evidence. Shared decision making (SDM) reflects the importance of these two complementary experts with a convergence of patient interests and values combined with clinical expertise and best evidence around the central ethic of patient autonomy.[1]

Medical innovation develops along a pathway of identifying clinical need, biomedical research and discovery, critical appraisal and synthesis, development of clinical practice guidelines (CPGs), and implementation into practice.[2] While CPGs arose from the evidence-based medicine (EBM) movement and integrate best evidence, they are developed for care providers, not to assist patients with decision making. Closing this loop of innovation to a patient requires exploration of an individual's values and preferences. Several studies have found that a substantial percentage of patients would like to play a more active role in their healthcare decisions.[3] Patient decision aids (pDAs) are tools to engage patients in this decision making. They are particularly suited for complex decisions that have multiple options with varying outcomes for which patients may attribute different values. Furthermore, in clinical situations in which outcome information is limited or uncertain, the best choice depends on the importance the patient places on each of the benefits, harms, and scientific uncertainties.[4] In dermatology, the quality of medical evidence has improved substantially, but little has been done to incorporate SDM. Herein, we discuss SDM in dermatology, the effectiveness of pDAs, and their potential role in dermatology.

Dermatology is a specialty particularly suited to SDM as the severity of most dermatologic diseases is defined by patients' experience of symptoms and adverse

psychosocial impact. Patients vary greatly in how they respond to dermatologic diseases as clinical determinants of severity often do not predict psychosocial impact. For example, some with severe acne may be unperturbed while others with few lesions may be highly distraught. Treatment decisions in dermatology are therefore particularly guided by personal characteristics, circumstances and preferences; beyond objective disease severity. Such decisions are especially important to share with patients who have a responsibility to self- manage chronic illness. Accordingly, the majority of treatment decisions in dermatology should be preference-sensitive. Thus, what patients feel is important (values) should be a major determinant of the decision process. This is a patient-specific dimension that cannot be adequately answered by physicians responding to the question: what would you do, doctor? These factors may include convenience of treatment, product acceptability, cost, risk or side effects, onset of effect, overall efficacy, mode of administration, and potential for remission. In limited research of decisional roles in dermatology, the vast majority of dermatology patients wish to be actively involved in treatment decisions – 71% for psoriasis and 80% for melanoma.[5,6] Furthermore, most dermatological conditions have several treatment options with no singular gold standard, and sparse supportive evidence for alternative options. Examples include treatment of hidradenitis suppurativa, prurigo nodularis or chronic pruritus. A framework for shared decision-making in dermatology is shown in Figure 1.[7] This provides dermatologists an opportunity to work with patients in designing pDAs that inform about multiple treatment choices and to effectively communicate uncertainty about available evidence, while also eliciting patient values and preferences. An example of a decision aid in psoriasis can be accessed at <http://www.wcri.ca/wp-content/uploads/2016/03/DECISION_AID-psx-v-Oct2012.pdf>.[8]

Beyond provision of information on disease and treatment, pDAs can be designed to establish the need for a decision, encourage deliberation of choices, clarify patient values and elicit preferences. While pDAs were initially developed as simple decision boards diagramming risks and benefits for use during a medical encounter; they are now available in multiple other formats including interactive videodiscs, online formats, audiotapes, audio guided workbooks, and pamphlets for use before and after encounters to encourage self-reflection and deliberation.

The preparation of these tools requires significant effort and rigorous methodology to ensure they are both user friendly, and scientifically accurate. The collection of decision aids is growing and promoted within some health systems (http://sdm.rightcare.nhs.uk/pda/; https://decisionaid.ohri.ca/AZinvent.php). Compared to standard care, pDAs have been shown to enhance knowledge about management options, reduce decisional conflict, encourage more active patient participation in decision making, and improve risk perceptions.[9] For example, use of decision tools has been linked to choice of more conservative options rather than more invasive options.[9] Use of the psoriasis pDA showed that patients tended to self-select treatment appropriate to their level of psoriasis severity.[10] Perhaps most importantly, decision tools are shown to improve 'decision quality' or 'the match between the chosen option and the values that matter most to the patient'.[11,12]

Despite these benefits, there is a paucity of pDAs in dermatology. Presently, those that do exist address psoriasis[7], basal cell cancer (BCC)[13], acne[14], and oral isotretinoin[15] and were developed heterogeneously according to international standards or without clearly established methodological criteria. A key issue for the application of

pDAs is practicality. Little is known about the degree of detail required to provide a beneficial effect on decision-making. In general, simpler pDAs may be more practical for use in a clinical setting. However, brevity may impose restrictions on provision of adequate information on the condition, the range of management options, and detail about specific benefits and risks. Nevertheless, pDAs may be underutilized in busy clinical practices.[16] Greater time invested in initial consultations to optimizing treatment decisions best suited to patients' preferences may enhance adherence and reduce time required in follow up consultations.

The Walter framework for individual decision-making at the end of life which was originally developed for screening decisions in older adults[17], but has been adapted for care of skin cancer, anchors decisions through quantitative estimates of life expectancy and then incorporate risks and benefits of screening, can be adapted for management choices in BCC (Fig. 2). A pictorial representation of risks and benefits for oral antipsoriatic therapy is shown in Fig. 3[7]. The final step involves incorporating the patient's own values and preferences in making a fully informed and individualized decision. Practical pDAs that can facilitate these difficult decisions in a way that is feasible within the expertise and time constraints of a busy clinical dermatologist are urgently needed.

CONCLUSION

Informed shared decision-making supports patient autonomy and patient centered care. This process can be facilitated by development of pDAs derived from high-quality evidence-based systematic reviews transformed into decisional tools by clinical experts, patients and educators. They should be developed with a specific view to enhancing patient comprehension, maximizing relevance, and to being validated for

such outcomes. Additionally, they should be designed to enhance, rather than interfere, with patient-doctor communication within busy clinical settings. To enhance accessibility and use, they should be readily available in the public domain. Given the variable psychosocial impact of skin disease on individuals and relative uncertainty regarding best treatments and their adherence in many dermatologic conditions, informed shared decision making should constitute a central component of dermatologic care. The paucity of pDAs to support this process in dermatology reflects an unmet need. We encourage researchers, clinicians, patients and funding agencies to develop, disseminate and use pDAs to facilitate SDM in dermatology.

REFERENCES

1. Towle A, Godolphin W. Framework for teaching and learning informed shared decision making. *BMJ* 1999;319:766–71.
2. Haynes B, Haines A. Barriers and bridges to evidence based clinical practice. *BMJ* 1998;317:273–6.
3. Kiesler DJ, Auerbach SM. Optimal matches of patient preferences for information, decision-making and interpersonal behavior: evidence, models and interventions. *Patient Education and Counseling* 2006 Jun 30;61(3):319-41.
4. O'Connor AM, Llewellyn-Thomas H, Stacey D, editors. IPDAS Collaboration background document. February 17, 2005. Available at: http://ipdas.ohri.ca/IPDAS_Background.pdf (last accessed 4 February, 2016)
5. Tan J, Stacey D, Fung K et al. Treatment decision needs of psoriasis patients: a cross-sectional survey. *J Cutan Med Surg* 2010;14:233-9.
6. Albrecht KJ, Nashan D, Meiss F et al. Shared decision making in dermato-oncology: preference for involvement of melanoma patients. *Melanoma Res* 2014;24:68-74.
7. Ottawa Health Research Institute, 2014b. Decision-aid development toolkit. Available at: https://decisionaid.ohri.ca/resources.html (last accessed April 16, 2016)
8. Tan J, Wolfe B. A patient decision aid for psoriasis based on current clinical practice guidelines. *Arch Derm* 2012;38:718-723. Available at: http://www.wcri.ca/wp-content/uploads/2016/03/DECISION_AID-psx-v-Oct2012.pdf.
9. Stacey D, Légaré F, Col NF et al. Decision aids for people facing health treatment or screening decisions. *Cochrane Database Syst Rev* 2014;1:CD001431.

10. Tan J, Wolfe B. Improved decisional conflict and preparedness for decision making using a patient decision aid for treatment selection in psoriasis: a pilot study. *J Cutan Med Surg* 2014;18(2):114-8.

11. Stacey D, Bennett CL, Barry MJ, Col NF, Eden KB, Holmes-Rovner M, Llewellyn-Thomas H, Lyddiatt A, Légaré F, Thomson R. Decision aids for people facing health treatment or screening decisions. *Cochrane Database Syst Rev* 2011 Oct 5;10(10).

12. Elwyn G, O'Connor A, Stacey D, Volk R, Edwards A, Coulter A, Thomson R, Barratt A, Barry M, Bernstein S, Butow P. Developing a quality criteria framework for patient decision aids: online international Delphi consensus process. *Bmj* 2006 Aug 24;333(7565):417.

13. Basal cell skin cancer: Should I have surgery or use medicated cream? Available at: https://www.healthwise.net/cochranedecisionaid/Print/PrintTableOfContents.aspx?docId=abp6164&sectionId=abp6165 (last accessed 4 February, 2016).

14. Acne: Should I see my doctor? Available at: https://www.healthwise.net/cochranedecisionaid/Print/PrintTableOfContents.aspx?docId=aa37670&sectionId=uf10096 (last accessed 4 February, 2016).

15. Acne: Should I take isotretinoin for severe acne? Available at: https://www.healthwise.net/cochranedecisionaid/Print/PrintTableOfContents.aspx?docId=aa37467&sectionId=uf10098 (last accessed 4 February, 2016).

16. Graham ID, Logan J, Bennett CL, Presseau J, O'Connor AM, Mitchell SL, Tetroe JM, Cranney A, Hebert P, Aaron SD. Physicians' intentions and use of three patient decision aids. *BMC Medical Informatics and Decision Making* 2007 Jul 6;7(1):1.

17. Walter LC, Covinsky KE. Cancer screening in elderly patients: a framework for individualized decision making. *JAMA* 2001;285:2750-6.