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Development and field testing of a consumer shared decision-making training program for adults with low literacy

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ABSTRACT

Objective: Given the scarcity of shared decision-making (SDM) interventions for adults with low literacy, we created a SDM training program tailored to this population to be delivered in adult education settings.
Methods: Formative evaluation during program development included a review of the problem and previous efforts to address it, qualitative interviews with the target population, program planning and field testing.
Results: A comprehensive SDM training program was developed incorporating core SDM elements. The program aimed to improve students' understanding of SDM and to provide them with the necessary skills (understanding probabilistic risks and benefits, personal values and preferences) and self-efficacy to use an existing set of questions (the AskShareKnow questions) as a means to engage in SDM during healthcare interactions.
Conclusions: There is an ethical imperative to develop SDM interventions for adults with lower literacy. Generic training programs delivered direct-to-consumers in adult education settings offer promise in a national and international environment where too few initiatives exist.
Practice implications: Formative evaluation of the program offers practical insights into developing consumer-focused SDM training. The content of the program can be used as a guide for future efforts to engage consumers in SDM.

1. Introduction

Shared decision-making (SDM) occurs when patients and healthcare professionals work together to make decisions about the patient's health based on best available evidence [1,2]. It necessarily involves information exchange and deliberation about test and treatment options and the benefits and harms of those options, as well as consideration of patient preferences and values [3]. As a midpoint between the paternalistic model of care and 'informed choice', SDM is an interpersonal and interdependent process between a clinician or clinical team and patient [4]. Shared decision-making has been identified as an effective method of reaching treatment agreements [5] and may improve affective-cognitive outcomes for patients [6]. Patients who are more informed also have more accurate risk perceptions and improved clinical outcomes [7].

Despite the benefits of SDM, involving consumers in SDM in clinical practice has, to date, had limited success [4]. There have been few attempts to engage consumers in SDM practices and

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fewer still to make SDM a clinical reality for individuals with low literacy and low education [8]. Adults with low literacy make up a large proportion of the population across Organization for Economic Co-operation and Development (OECD) countries [9–11] and have higher rates of illness and chronic disease [12]. They are less likely to understand the concept of SDM and are less familiar with medical language and the healthcare system [13]. They may also perceive a greater power imbalance between doctor and patient than individuals with higher levels of literacy [14] and may ask physicians fewer medical and lifestyle-related questions during consultations [15]. Patients with low literacy also report less patient-centered communication and less satisfaction with their healthcare providers [16].

Despite the current lack of engagement, there are a number of potential ways to promote SDM for adults with low literacy. Patient-mediated decision tools such as decision aids, option grids and question prompt lists could be designed using low literacy design principles (such as those outlined in the International Patient Decision Aid Standards chapter on addressing health literacy) and trialed for use in this population [8]. Shared decision-making coaching, training or education programs could also be used to support consumers with low levels of literacy to read, understand and use the decision tools for reaching decisions about their health.

We adopted the latter approach and created a SDM training program for consumers with low literacy. This program was to be delivered as 2, 3-h lessons within a larger Australian program-based on the UK *Skilled for Health* initiative [17] – to train lower-literate adults in health literacy in adult education settings (See Appendix A for the full program outline). The adult education context is considered an appropriate and under-utilised avenue for improving health literacy among adults with low levels of literacy and numeracy [18,19]. In Australia (and many other OECD countries) adult education programs are widely available and provide a previously untapped infrastructure to deliver education to improve health literacy to adults with lower literacy using trained adult literacy teachers. Our program utilised this existing infrastructure to deliver an educational program to improve health literacy within an existing adult literacy and numeracy program using Functional Contextual Education methods [20]. This approach to adult learning embeds education within topics that are of relevance and interest to adult learners which promotes greater engagement among students [20].

Shared decision-making was included as a core component of the health literacy program in recognition of its importance in contemporary healthcare [3]. Health decision making is required at every level of healthcare [3] and is an important aspect of communicative and critical health literacy as defined by Nutbeam [21]. Nutbeam's levels of health literacy reflect the different skills required to obtain and use health information in ways that lead to greater autonomy and empowerment in health decision-making [21]. Aligning with the communicative and critical levels in Nutbeam's model, the SDM training program promoted skills to obtain relevant health information, derive meaning and apply information, and share decision-making with healthcare professionals.

Specifically, the SDM training program aimed to (a) increase knowledge of the concept of SDM amongst adults with low literacy; (b) provide learners with the necessary skills to engage in SDM; (c) promote self-efficacy to engage in SDM. The final version of the SDM training program is currently being evaluated in a randomised controlled trial involving 23 adult education colleges throughout New South Wales, Australia. This paper reports the formative evaluation and field testing of the SDM training program prior to its broader application in an adult learning environment.

2. Methods and results

Formative evaluation is a set of activities designed to develop and pre-test program materials and methods to ensure relevance to the target population [22]. There are several stages of activities considered part of formative evaluation, including: Stage 1; reviewing the problem and previous efforts to address it; Stage 2; formative evaluation to understand the target population; Stage 3; program planning; and Stage 4; pre-testing intervention methods and materials [22]. We conducted activities within these stages as part of formative evaluation of the SDM training program.

2.1. Stage 1: reviewing the problem and previous efforts to address it

2.1.1. Methods

A variety of approaches have been used to support patients and clinicians to achieve SDM including decision aids, option grids, and question prompt list interventions which address specific health issues [23–25]. Within the context of a community-based adult education setting, students' ages and health status are varied so promoting SDM by teaching use of decision tools or option grids developed for specific clinical contexts is not appropriate or possible. However generic consumer questions may be a feasible way to engage adult learners in SDM. Generic questions designed to elicit evidence to support clinical decisions can be taught to consumers and can increase the amount of information provided by healthcare professionals [26].

We conducted a review of the literature to identify generic question sets which could be used to promote SDM within the context of a community-based adult education setting. An additional review was conducted to identify existing SDM training courses for consumers.

2.1.2. Results

From the literature, we identified three sets of generic consumer questions; Ask Me 3 [28], Smart Health Choices [27] and AskShareKnow [26]. See Table 1. Whilst the Ask Me 3 questions were designed to promote communication between healthcare providers and patients but not to address SDM, the AskShareKnow and Smart Health Choices questions were designed specifically to promote evidence-based SDM in a variety of clinical encounters. Therefore, the AskShareKnow and Smart Health Choices questions were included in formative evaluation, whilst the Ask Me 3 questions were not.

Neither the AskShareKnow nor the Smart Health Choices generic question sets had been trialed with adults with low literacy

Table 1
AskShareKnow, Smart Health Choices and Ask Me 3questions.

AskShareKnow questions [26]	Smart Health Choices questions [27]	Ask Me 3 questions [28]
(a) What are my options?	(a) What will happen if I wait and watch?	(a) What is my main problem?
(b) What are the possible benefits and harms of those options?	(b) What are my test and treatment options?	(b) What do I need to do?
(c) How likely are each of those benefits and harms to happen to me?	(c) What are the benefit and harms of those options?	(c) Why is it important for me to do this?
	(d) How do these benefits and harms weigh up for me?	
	(e) Do I have enough information to make a choice?	

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