Evaluation of a Health Literacy Program for Chronic Conditions

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ABSTRACT

Background: Although much is known about health literacy in concept and practice, more research is needed to understand the mechanisms that improve health literacy and result in healthy behavior change. This is particularly so for those at risk of or living with chronic conditions who reside in communities experiencing socioeconomic disadvantage. **Objective**: The program aimed to improve the prevention and management of chronic conditions by responding to health literacy needs. **Methods**: A health literacy program, underpinned by Ophelia principles, was developed in consultation with three Neighbourhood Houses located in areas of socioeconomic disadvantage. Four 7-week group programs were delivered by a multidisciplinary team of academic health professionals. The evaluation aimed to explain how the design, content, and approach to delivery resulted in healthy behavior change and increased health literacy for the participants. Four focus groups were conducted to elicit feedback about the participants' experience of the program and recommendations for future programs. Data were thematically analyzed. The focus groups were attended by 22 (43%) of the total 51 program participants. Most of the participants were women with one or more chronic condition and residing in an area of socioeconomic disadvantage. **Key Results**: Four major themes were identified including the components of self-determination theory (SDT) (autonomy and competence and relatedness) and a separate, but related theme of empowerment. Recommendations for improving future programs were categorized separately. **Conclusions**: The SDT framework is a useful and novel approach to explaining the evaluation outcomes, the application of the Ophelia principles' underpinning design of the program, and the contribution of a multidisciplinary team of academic health professionals. Future programs will benefit from the SDT as a planning and evaluation framework, as well as understanding the long-term effects of the program within the broader community. [**Health Literacy Research and Practice**. 2017;1(3):e100-e108.]

Plain Language Summary: A team of health professionals developed a 7-week group program that they delivered in the community setting to people who were living with or at risk of developing chronic conditions. The evaluation showed the benefit of providing health information in ways that can be understood and acted upon, as well as the value of a group program that fosters participation.

The capacity to understand and recall health-related information to make decisions is fluid and situationally dependent. The ability to find, appraise, understand, and act on information is known as health literacy and reflects one's personal characteristics and social resources (Jordan et al., 2013). Globally, there is an increasing awareness of the relationship between health literacy and health outcomes, with health literacy thought to be a better predictor of health status than education, socioeconomic status, employment, race, or gender (Weiss, 2007).

When health literacy is low, people have less knowledge of conditions, treatment, and health determinants (Pignone, DeWalt, Sheridan, Berkman, & Lohr, 2005). This results in a greater number of preventable hospital admissions, increased use of emergency services, and more medication and treatment errors (Pignone et al., 2005). The health care system is becoming more complex to navigate (Schumacher et al., 2013), and this particularly effects how people self-manage chronic conditions as that requires the ability to respond to test results, meet multiple

health care providers, and adhere to complicated medication regimens. Additionally, factors such as stress and anxiety can affect health literacy (Cornett, 2009).

Originally understood as a measure of individual capacity (and deficit), the concept of health literacy has matured, and now takes a more reflective view of the health care system (McCormack, McBride, & Paasche-Orlow, 2016). This development is positive, as it moves away from a deficit model that runs the inherent risk of victim-blaming. Much of the earlier research focuses on low health literacy as a clinical risk within the context of the biomedical model of health and promotes increased patient education and compliance (Hill, 2004) (i.e., improving the readability of medication labels) (Ngoh, 2009). This perspective views health literacy as a risk factor and emphasizes the need for people to improve their health literacy skills. In contrast, the developing model of health literacy places a greater emphasis on health care provider responsibility and improving accessibility and equity within the health care environment (Hernandez, 2013). Further, health literacy is becoming recognized as the "junction between literacy, health and healthcare" (Australian Commission on Safety and Quality in Health Care, 2012, p. 2). Conceptualized in this way, health literacy reaches beyond clinical health care settings into the broader community where it is positioned as a personal asset (Raynor, 2012). The asset framework encompasses the social model of health and emphasizes context specificity, and the enhancement of consumer empowerment and autonomy through targeted skill development and communication (Nutbeam, 2008). Therefore, emphasis is placed on supporting people to understand and use health information (functional health literacy), the role of health service providers (interactive health literacy), and a supportive environment (critical health literacy) in the context of everyday life. Application of this health literacy framework to this evaluation helped build an understanding about mechanisms for improved health literacy and behavior change.

Although the links between health literacy and health outcomes have been well established, less is known about the effectiveness of health literacy interventions due to not having tested evaluation measures and methods (D'Eath, Barry, & Sixsmith, 2012). To understand more about successful implementation of health literacy interventions, a focus on examining behavior change as a consequence is warranted (Ng et al., 2012). The optimal evaluation timing and methods are as yet unknown; therefore, one potential solution is to measure the intervention's effectiveness by evaluating behavior change using a framework such as self-determination theory (SDT) (Silva, Marques, & Teixeira, 2014). Recently, SDT has been applied in the health care setting to identify elements that contribute to effective change of health behaviors (Deci & Ryan, 2012; Ng et al., 2012; Silva et al., 2014). SDT is a useful framework for explaining motivational dynamics in health care (Silva et al., 2014) and has been used to promote physical activity and dietary behavior change (Teixeira, Silva,

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Mata, Palmeira, & Markland, 2012), exercise (Teixeira, Carraça, Markland, Silva, & Ryan, 2012), and self-management of chronic musculoskeletal conditions (Hurley et al., 2016).

Intrinsic motivation is at the core of SDT and is dependent on autonomy, competence, and relatedness (Ryan & Deci, 2000). Autonomy occurs when someone identifies with the importance of a health behavior (Ryan, Patrick, Deci, & Williams, 2008). To adopt new behaviors requires that the person is competent and this can be achieved through feedback from practitioners until the person experiences behavior mastery (Ryan et al., 2008). Even though affording autonomy and supporting competence are more likely to improve adherence, behavior change is challenging and people are more likely to adopt changes if they are promoted by those they feel connected to and trust—when there is a sense of relatedness (Ryan et al., 2008). Incorporating the principles of SDT to the content and delivery of a health literacy program requires acknowledgement of the difficulty of making changes, clearly presenting the choice to make a healthy change, providing specific advice about tackling the new behavior, and boosting competence through feedback and social support.

Community-based health literacy programs improve health outcomes by supporting the skill development of community members through social participation, and by locating health promotion "within its social, economic and political contexts" (Estacio, 2013, p. 1057). A collaborative, community participation approach fosters empowerment and is reflected within the Ottawa Charter's explanation of health promotion as, "the process of enabling people to increase control over, and to improve, their health" (World Health Organization, 1986). This approach encourages learners to become active agents in health education and community development (Estacio, 2013), rather than passive recipients of knowledge (Freire, 1972).

Contemporary understandings of health literacy focus on the many determining factors that require a participatory approach to first identify, then address health literacy needs. The Ophelia approach enacts this understanding by applying a set of eight principles (outcomes focused, equity driven, needs diagnosis, co-design, driven by local wisdom, sustainable, responsive, and systematically applied) that ensures the potential to improve health and equity through health literacy responses is optimized (Batterham et al., 2014; Batterham, Hawkins, Collins, Buchbinder, & Osborne, 2016; Beauchamp et al., 2017). These principles have been applied in this project to foster authentic engagement with program participants. This is the first time that these principles have been applied outside the structured Ophelia approach, testing the applicability of these principles more broadly to promote equity, participation, and empowerment.

OBJECTIVE

This article presents the evaluation of a community-based health literacy program, focusing on how the design, content, and approach to delivery have resulted in increased health literacy and healthy behavior change for the participants.

METHOD
Intervention

This community-based health literacy program aimed to (1) develop participants' ability to communicate effectively with health care providers; (2) understand their own behaviors; and (3) recognize the effect of those behaviors on the prevention and self-management of chronic conditions. The program content, designed for delivery in 2-hour sessions with 6 to 10 participants, was developed by a multidisciplinary team of academic health professionals in collaboration with representatives from three Neighbourhood Houses located within areas of socioeconomic disadvantage. Neighbourhood Houses are centers that bring local people together to connect, learn, and contribute in their local area through social, educational, recreational, and support activities using a community development approach (Neighbourhood Houses Tasmania Inc., 2014).

The health literacy program was promoted to community members by the coordinators of the three Neighbourhood Houses specifically targeting people with or at risk of chronic conditions. Each session included 1 hour of topic discussion (focusing on physical activity, nutrition, and healthy decision-making), and 1 hour of physical activity. Physical activity was integral to all sessions to provide regular practice opportunities in a supportive environment to achieve both behavior change and confidence. To ensure continuity within each program, the same exercise physiologist delivered the physical activity. The program was designed to be flexible and adaptive to the needs of each group, and participants could choose to attend one or more sessions according to their preferences. The sessions followed an action learning approach (Revans, 2011), whereby the participants explored their own health concerns with the facilitators and other group members within the context of the session topic. This afforded the participants the opportunity to share insights into each other's concerns, thus promoting active participation, collegiality, and support. An overview of the program topics and facilitators are presented in **Table 1**.

TABLE 1

Description of the Community-Based Health Literacy Program

Session	Title	Facilitator(s)	Content
1	Exercise is medicine	Exercise Physiologist Physiotherapist	Common myths about exercise The physical and mental benefits of being physically active Matching exercise to life stages and ages How to fit extra (incidental) physical activity into everyday life The opportunity to try different kinds of exercise and activity
2	Questions for the right answers	Social Worker Exercise Physiologist	How to improve communication between consumers and health service providers Techniques for exchanging information with health service providers Practicing communication skills through role play
3	Food myths	Dietitian Exercise Physiologist	Common myths about food Information about healthy food choices Practice activities including reading and understanding food labels
4	Staying on track	Health Psychologist Exercise Physiologist	Setting health goals Developing strategies to reach health goals Maintaining motivation Tracking progress
5	Understanding pain	Physiotherapist Exercise Physiologist	Causes of pain Kinds of pain Management of pain
6	Understanding the body	Physiotherapist Exercise Physiologist	Basic anatomy Using anatomical models to better understand the location and function of various body parts
7	How far have we come	Nurse Exercise Physiologist	Review of all previous sessions using type 2 diabetes as an exemplar Facilitate group discussion of participant experience of the program

Design

A convenience sampling method was used. Outcome evaluation was conducted through focus groups held directly after the final facilitated group session at each site. The Neighbourhood House coordinators verbally informed all those who attended the programs about the evaluation focus group at each weekly group session. Focus groups have been used as a method to elicit responses from "hard-to-reach" subpopulations (Bonevski et al., 2014) and to facilitate participants' communication of rich details of complex experiences and the reasoning behind their actions, beliefs, perceptions, and attitudes (Morse, 1994). This method was

also chosen to mitigate potential literacy problems and to capitalize on participant familiarity with each other and the group sharing process inherent in the program.

Four focus groups were facilitated by one of two project team members (S. E. or R. J.) who had not provided direct input into the delivery of the program. A semi-structured interview guide was developed to elicit participant views of the effect of the program on health behavior change. Three of the focus groups were recorded and the data transcribed and de-identified. Where one recorder failed, notes were hand recorded by the facilitator. Focus groups lasted between 30 and 45 minutes. Ethics approval was received from the Tasmanian Human Research Ethics Committee H0015528.

Data Analysis

A general inductive approach was used involving detailed reading and re-reading of the raw data and developing categories (Thomas, 2006) by two of the authors (A. W., R. J.). Data were organized and categorized in a spreadsheet. From this initial coding framework, relevance to an existing model of behavior change, SDT (Ryan & Deci, 2000), emerged. An additional category, empowerment, was also developed and refined. Data were then coded and ordered by predominance against the four categories autonomy, relatedness, competence, and empowerment by four authors (A. W., R. J., H. B., S. E.). Disagreements were discussed until consensus reached. Subthemes were then developed within the four higher-order categories. Recommendations for improving future programs were also captured.

RESULTS
Evaluation of Participants

Of the 51 program participants, 22 (43%) participated in the evaluation. The age of the participants ranged from age 17 to 70 years, 71% were women, and 3 (9%) identified as Aboriginal or Torres Strait Islander. English was the first language for all participants. All but two participants experienced at least one chronic condition. The most common illness was chronic back pain (50%), followed by depression (38%), arthritis (35%), type 2 diabetes (26%), and hypertension or cardiovascular disease (24%).

Themes

Analysis revealed four major themes and four subthemes. The themes of autonomy, competence, relatedness, and empowerment were evident across the participant data. Recommendations, a fifth theme (with three subthemes), was specifically included for quality improvement purposes.

Data from participants have been presented as a collective voice to ensure anonymity. See **Table 2** for example quotes from each theme. There was no evidence of gender- or age-related differences in the responses.

Autonomy. The theme of autonomy was evident across all three areas of focus for the content of the program: physical activity, nutrition, and health decision-making. Participants reported autonomous actions including increased incidental physical activity, changing dietary habits, and choosing a new doctor. This suggests that the program enabled the participants to take action in areas of most relevance to them, and that change was not limited to one area of focus. The effect of the program was evident in the new or additional actions reported by the participants. Importantly for the participants, these new actions were readily incorporated into their usual activities, which is indicative of actions leading to positive change.

Competence. The theme of competence was closely related to autonomy; however, it was not necessarily evidenced by action. Competence referred to reports of knowledge or skills the participants learned that provided insights about their planned activity or their greater awareness of health choices. These insights were indicative of their application of newly acquired knowledge to their own situation. The context in which the participants applied this knowledge varied and predominantly focused on nutrition and physical activity.

Relatedness. The theme of relatedness comprised two subthemes titled "group dynamics" and "the spread." Group dynamics referred to the relationships between group members, and the spread referred to the relationships between group members with others outside of the group. The participants' feedback about the relationships within the group was positive. The comments were indicative of trust, peer support, and normalizing their experiences of managing their health through shared stories. The program participants readily shared information about what they had learned in the sessions with family members, their workplace, and other friends within the community. The spread of health messages to other parts of the community is further evidence of the group's effect. For example, the second program run in one of the communities had almost double the number of participants compared to the first program, and a small number of these had never previously attended the Neighbourhood House.

Empowerment. The theme of empowerment consisted of two subthemes: "approach" and "awareness." Approach related to the way the program was delivered, whereas awareness related to feedback received about the changes in the participants' level of mindfulness about their health issues. The program

TABLE 2

Themes, Subthemes, and Example Quotes

Theme	Subtheme	Example Quotes
Autonomy		"I've also put in place a transition to retirement plan because of the mind map exercise we did. … It's been life changing"
		"I've increased my fruit intake. … I've increased my vegetable intake too. … More aware of the need to eat fruit"
Competence		"I think twice about picking something up in the supermarket. I read labels more than I would have done"
		"… I have a better understanding of the kind of exercise I need for balance and my back. … I've put things into practice that I can manage, I've designed my own program"
Relatedness	Group dynamics	"there's a bond between us, look out for your neighbour, your friend"
		"… [Things were explained] in plain language and although it was sort of serious, they didn't take our response too seriously. Every session we all managed to have a good laugh"
	The spread	"I've talked about the exercise program for my back and they [friends and family] wished they'd come"
		"I've been talking to others about the program"
Empowerment	Approach	"Giving us information about the 'how to.' When you go to the doctor, he might say, for example, lose 5 kg, but no explanations of how or why, especially with exercise"
		"Very specific and relevant information. You [the facilitators] might think it's general, but it really hit home"
	Awareness	"It made me aware that I've got to get up and do something to better myself"
		"I know what I need to do but saying it and doing it are different things. The program has reinforced some of what I have already learnt. It's helped me to know I'm on the right path."
Recommendations	Additional content	"I'd like to do another program like this"
	Behavior change	"Being consistent is problem"
		"Getting into the right headspace"
	Group composition	"Maybe a focus on a particular group like the young mums or the diabetic group"
		"Have more males come to the group"

was designed to be responsive to local needs and used the collective wisdom of the participants by drawing on their shared experience of living with chronic conditions and their shared learning within the program. This approach was reflected in the participants' feedback about the relevance and applicability of the information provided. The participants reported shifts in their thinking such as thinking differently about the type of exercise and physical activity required to be effective. One participant explained: "I kept trying to do the exercises myself and it weren't [sic] working, just making things worse for me because I'm trying too hard, too heavy, thinking that's

the way you had to do it and it wasn't helping at all, so these exercises seem to be helping a lot." The participants increased their awareness about health-related issues in ways that made behavior change seem more achievable, bridging the gap between knowledge and action through small incremental steps.

Recommendations

Feedback and recommendations for improving the program were mostly positive. Three subthemes were identified by participants as significant to the program: behavior change, program content, and group composition. Partici-

pants identified several factors that make behavior change difficult including lack of motivation, negative thinking, and the difficulty of change in general. Participants requested more sessions and content improvements to build on and support new knowledge and skills. Participants also made recommendations about the composition of the group and suggested targeting subgroups in the community. Minimal negative feedback was received, which may be a reflection of the way the program sessions responded to the expressed needs and interests of the participants; subsequently, this "co-creation" approach ensured the relevance and responsiveness of the program.

DISCUSSION
A Framework for Evaluating Health Literacy Interventions

This study responds to recommendations to incorporate theories of behavior changes, such as SDT, as a framework for planning and explaining health promotion programs to better understand the active components of interventions that result in behavior change (Ng et al., 2012; Silva et al., 2014). The themes of autonomy, competence, and relatedness were evident to varying degrees across the data. Autonomy was most evident in the description of choices that the participants made about the range of health behaviors changes (physical activity, nutrition, and health management). Competence was demonstrated by an increase in knowledge and skills related to enacting behavior change. The element of relatedness comprised several aspects, including the relationships with the facilitators, mode of program delivery, and the relationships between members of the group and the wider community. The approach of the facilitators established an environment that was conducive to supporting autonomy, competency, and relatedness.

Beyond the components of SDT, a separate but related theme of empowerment was identified to refer to the ways that the participants had gained control over factors and decisions that shape their lives (Nutbeam, 1998). Inclusion of empowerment as a theme is consistent with contemporary understandings of health literacy that are aligned with health promotion and move beyond the narrow view of health education (Abel, 2008). The empowerment theme consisted of two aspects: the approach used by the facilitators to understand the factors that determine the health of the participants, and the raised awareness of the participants created by addressing their knowledge and skills to change the factors that constitute their health chances. Specific components of the program previously identified as contributing to empowerment included personal goal setting, decision-making

about learning, and self-evaluation (Hui & Tsang, 2012). Empowerment appeared in the participant feedback as an outcome, and as part of the process (bi-directional). However, the causal direction was not as important as the experience of empowerment together with increased health literacy, as this enables the participants to have raised awareness and take action (Eyüboğlu & Schulz, 2016). Emphasizing empowerment as part of improving health literacy is integral to achieving critical health literacy, described by Nutbeam (2008) as the ability to analyze and use information to act to overcome structural barriers to better health. Critical health literacy enables community action and, in this way, health literacy is distributed among social networks (Batterham et al., 2016).

OPHELIA PRINCIPLES

The Ophelia Principles underpinned the program (Beauchamp et al., 2017). A strength of this study was the collaborative way in which the community was involved in the design and planning of the program. This required sufficient flexibility to respond to participants and to develop program content in an iterative way, based on their reflections and feedback. For this to occur, the facilitators needed to be skilled, knowledgeable, and comfortable with an otherwise informal and flexible approach. By drawing on collective wisdom within the groups and encouraging shared stories, the facilitators fostered the development of supportive relationships between group members. The involvement of the Neighbourhood House coordinators was critical to the success of the program to promote and target participants, as well as to ensure contextually appropriate content and delivery style. This included minimal use of didactic style of delivery, types of physical activity, and ensuring resources provided to participants had low literacy demands.

LIMITATIONS

Several limitations exist with this work. Although the program was designed to improve the health literacy of the participants, no formal pre- and post-measures of health literacy were undertaken; however, the focus of this study was on behavior change as evidence of health literacy improvements that allowed for the mechanisms of how this occurred to emerge within the SDT framework. Holding the focus groups after the final session of program may have limited participation, and these participants may have viewed the program more favorably, thus influencing the positive nature of the feedback and the themes that emerged. However, this approach was considered contextually appropriate and garnered views from nearly half of the participants. Due to pragmatic constraints, collection of data relating to age and health

status were only collected at the start of each of the four programs. This precluded capturing data from participants who attended later sessions; therefore, health demographics may not be generalizable. In addition to these limitations on data collection, the participants in the focus group were drawn from a convenience sample; therefore, this evaluation has limitations in relation to the small number of participants and the generalizability of the findings. However, the characteristics of those who participated in the focus groups were representative of all program participants.

FUTURE PROGRAMS

Elements of this intervention's process and programming are useful for others in developing health promotion programs that include the use of a theoretically informed framework to measure change. The multidisciplinary team of academic health professionals that worked together with community members to develop the program included the disciplines of social work, psychology, exercise physiology, physiotherapy, dietetics, and nursing. A strength of this mix was that it provided a range of different skills to meet the varying needs of individual participants particularly in relation to their values and perspectives on chronic conditions. The team bridged the biomedical and social models of health by combining their clinical expertise with a social determinants of health approach. This ensured a holistic approach that genuinely engaged with the community and responded to their needs. This kind of authentic community engagement also builds the capacity of people to positively affect their own health and that of their community (Centers for Disease Control and Prevention – Division of Community Health, 2013). A key strength of the program was that the same exercise physiologist attended all sessions that promoted continuity and built rapport, which are critical elements of program design for those at risk of or living with chronic conditions (Centers for Disease Control and Prevention – Division of Community Health, 2013). Evidence of the positive outcomes from this relatedness include the ongoing relationship established between the group members, some of whom continue to meet weekly for physical activity and a subsequent invitation to the dietitian and social worker for further sessions.

Future programs would benefit from SDT together with empowerment, as a planning and evaluation framework as well as from incorporating longer-term follow-up, particularly in relation to the effect of "The Spread" in the context of critical health literacy. Use of community-based participatory research approaches (World Health Organization, 2009) such as the application of the Ophelia principles, may further assist in engaging and empowering communities by developing an understanding of where people (participants) are in their health literacy journey (what they understand). Finally, the use of contextually relevant approaches to measure health literacy, prior to the intervention, such as the Conversational Health Literacy Assessment Tool (A. Beauchamp, December 21, 2016, personal communication), should be considered to further understand and respond to identified health literacy needs.

CONCLUSION

This study makes important contributions to the literature regarding evaluation of health literacy interventions through its emphasis on understanding the underlying mechanisms that result in behavior change. Information from this study may be helpful for others planning to undertake similar programs. Future evaluation suggestions include longer-term follow-up of participants, use of appropriate health literacy measures, and community-based participatory research approaches to further engage and empower communities.

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