Personal goals among women with breast cancer: a scoping review and cohort study

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Preface to the Thesis

1. Ethics approvals

Prior to the conduct of the cohort study (Chapter 5), ethics approval for the study was obtained from the Research Ethics Boards of the Ottawa Hospital Science Network (OHSN-REB) and the Canadian College of Naturopathic Medicine on March 14, 2017 and April 24, 2017, respectively. Ethics approval was not required for the conduct of the scoping review (Chapter 3).

2. Authors' contributions

Chapter 2 - Personal goal-setting among women living with breast cancer: protocol for a scoping review

AC planned the study, drafted the protocol, conducted data analysis, and wrote the manuscript. DF and JP provided content and methodological expertise and commented on the drafts of the protocol. LS and AC designed the search strategy. AC and IP conducted the screening and data extraction. All authors read and approved the final manuscript.

Chapter 3 - Personal goal-setting among women living with breast cancer: a scoping review

AC planned the study, conducted data analysis, and wrote the manuscript. DF, JP and DS provided content and methodological expertise throughout study design and analysis and commented on manuscript drafts. LS and AC designed the search strategy. AC and IP conducted the screening and data extraction. AC, DF, JP and DS read and approved the final manuscript. All authors will read and approve the final manuscript before submission for consideration of publication.

Chapter 4 - Personal goals of women recently diagnosed with breast cancer: Protocol for a cohort study

AC planned the study, drafted the protocol, conducted data analysis, and wrote the manuscript. DF, JP and DS provided content and methodological expertise and commented on drafts of the protocol. SY, AP, JE and SA provided content and program expertise. All authors read and approved the final manuscript.

Chapter 5 - Personal goals among women recently diagnosed with breast cancer and participating in an integrative oncology educational program: a prospective, observational cohort study

AC planned and designed the study, collected all data, conducted data analysis, and wrote the manuscript. DF, JP and DS provided content and methodological expertise through study design and planning, data collection and analysis, and commented on drafts of the manuscript. SY, AP, JE and SA provided content and program expertise. AC, DF, JP and DS read and approved the final manuscript. All authors will read and approve the final manuscript before submission for consideration of publication.

Abstract

Background: A breast cancer diagnosis may interfere with personal goal-setting, goal pursuit and well-being. Understanding the factors that enable or hinder personal goal-setting and pursuit among women with breast cancer can be a useful element of patient-centred care provision.

Objective: To examine the content and pursuit of, and published literature regarding, the personal goals set by women with breast cancer.

Methods: *Study 1* was a scoping review of the published literature on personal goal-setting by women with breast cancer. *Study 2* was a mixed-methods, cohort study with women recently diagnosed with breast cancer to identify their goals, whether they were able to pursue them, and barriers and facilitators of their goals.

Results: *Study 1:* Twelve studies were included. Eight studies included an intervention; completeness of reporting intervention elements varied widely. None of the studies used validated instruments to elicit personal goals. *Study 2:* Eight participants enrolled and six completed the study. Health, psychological, social, and leisure goals were commonly identified. Women were moderately successful at pursuing their important goals. Perceived enablers and barriers to goal pursuit were identified.

Conclusion: Findings on personal goals and personal goal-setting interventions that could help facilitate the development or enhancement of interventions for women with breast cancer to set and pursue their important personal goals.

Chapter 1: Prologue

1.1 BACKGROUND

1.1.1 Personal Goals

We all have personal goals. A *personal goal* can be thought of, simply, as a statement of an outcome, event, or state of being that an individual wants to achieve or strive for, though it may or may not be stated aloud.[1,2] Personal goals articulate the values, activities, or aims that are important to an individual.[3-6] In the field of psychology, personal goal-setting is often considered important elements of motivation and action,[2,7,8] and can be characterized in various ways. Characterizations referenced in this thesis include:

Goal hierarchy: Personal goals can be thought of in terms of a hierarchy, where some are high-order goals (or "be" goals, such a "be happy"), which are achieved by mid-level (or "do" goals such "spend time with my kids") goals which are themselves pursued through low-order goals ("have dinner together on Fridays"). Generally, the higher the goal level, the more time and actions over a lifespan are required for the pursuit of that goal.[1,9] Each person usually has a goal system where one goal in an individual's system may influence or be influenced by other goals. The pursuit of some lower-order goals (e.g. saying hello to the coffee shop clerk) can help a person achieve a higher-order goal (e.g. being a good person).[1,10,11] For the present research, the focus is on mid-level "do" goals.

Idiosyncrasy: Personal goals may be unique and idiosyncratic to an individual (e.g. "read one biography every week") or more normative across a population (e.g. "spend more time with my family").

Content: The content of a goal can itself be characterized in various ways. In this thesis, I characterize goal content in two main ways: by thematic domains that describe the type of

goal being pursued (e.g., health, social, work), and by directionality of its pursuit[1] (i.e. approach [do more], avoid [do less], maintain [do the same]).

The setting and pursuit of personal goals characterizes much of everyday life. Goal-setting theory holds that the conscious setting of goals is an important motivator that predicts performance.[5] The literature suggests associations between the type of personal goals set (e.g., self-concordant goals, approach goals), successful goal pursuit or goal progress, and well-being.[2,8,12-17] Pursuit of challenging yet achievable goals may be a key mediator of the relationship between personal goal-setting and well-being.[15,16] Goal hindrance, when a person is prevented from pursuing a goal successfully, is associated with lower psychological well-being.[18,19]

An individual's health is significantly associated with how they assess their own well-being.[14,20] Major health events such as the diagnosis of cancer or serious illness can change the goals that people pursue through the addition of new goals, the disengagement from existing ones, or the shift in the focus and priority of goals such as from extrinsic to more intrinsic (i.e. health-related) goals.[21-23]

1.1.2 Breast Cancer

Breast cancer is the most frequently diagnosed cancer among Canadian women, affecting more than twice the number of women than lung cancer, the second most diagnosed cancer.[24] Undergoing breast cancer treatment can have many side effects including fatigue, pain, physical limitations, premature menopause, and poorer cognitive functioning.[25-27] In the first year following a breast cancer diagnosis, psychological well-being often decreases, with a majority of women experiencing some degree of episodic or chronic distress, anxiety or depression.[28-35] For some women, depression may persist for many years after diagnosis.[36] Providing supportive care for psychological well-being can be beneficial for many women with breast cancer.[37]

1.1.3 Patient-Centred Outcomes

Striving to make health care more patient-centred has become increasingly important.[38,39] Integrative oncology, the field of integrating evidence-based complementary therapies and medical treatment, emphasizes patient-centered care and coordination between providers and patients.[40-43] Patient-centred care values outcomes that are important to the patient alongside clinical outcomes, such as survival.[44,45] Personal goals can be manifestations of the outcomes that are important to an individual and thus act as sources of motivation and frameworks for action. Personal goals are an important component to understanding what women are thinking about and the ways in which women want to focus their resources, such as time and physical energy, when living with a breast cancer diagnosis. For institutions and organizations interested in patient-centred oncological care, particularly integrative oncology, where patient-centred care is a key tenet, personal goals can help providers of supportive care and treatment understand women's important motivators and the ways in which women want to focus their resources, such as time and physical energy, when living with a breast cancer diagnosis.

1.1.4 Existing Literature on Personal Goals Among People with Cancer

Cancer and its treatment adds new constraints to an individual's time and both physical and mental energy to pursue personally important goals.[21,46] A higher burden of breast cancer-related physical symptoms has been associated with a reduced ability to pursue goals along with psychological distress.[47] The ability to engage in new goals is positively associated with subjective and emotional well-being;[48] however, the dynamics of such goal pursuit and the personal goals that can be successfully pursued within the context of a major life event such as breast cancer diagnosis and treatment is less clear.

1.2 RATIONALE

Women with breast cancer may turn to integrative oncology centres aiming to be more active participants in their healing and to improve their coping mechanisms.[49,50] How can these programs, and others that are also concerned with providing patient-centred care and support to women living with breast cancer, best support these women? Understanding the personal goals that women with breast cancer have for themselves and the factors that enable or hinder pursuit of their personal goal pursuit can be a useful component of patient-centred care provision. While a previous systematic review collated research on the life goals of people living with any type of cancer,[22] to our knowledge, there has been no assessment of the literature specifically focussed on goal-setting among women with breast cancer.

1.3 OBJECTIVES

This thesis consists of two interrelated studies that aim to examine several aspects of the personal goals of women with breast cancer. In the first study, I conducted a scoping review that aimed to chart the existing evidence on personal goal-setting among women with a breast cancer diagnosis. Second, I conducted a mixed-methods cohort study with women recently diagnosed with breast cancer to identify their goals, whether they were able to pursue them, and their perceived barriers and enablers of their goal pursuit.

1.4 OVERVIEW OF THE THESIS AND INCLUDED MANUSCRIPTS

This thesis includes four manuscripts related to the two studies. Chapters 2 and 3 describe the protocol and report (manuscripts #1 and #2, respectively) on the conduct of the scoping review. Chapters 4 and 5 describe the protocol and report (manuscripts #3 and #4, respectively) on the conduct of the cohort study. The protocols for both studies have been previously published and publication details are provided in each chapter.

1.5 REFERENCES FOR CHAPTER 1

1. Austin JT, Vancouver JB. Goal constructs in psychology: Structure, process, and content. Psychol Bull. 1996;120:338–75.
2. Emmons RA. Personal strivings: An approach to personality and subjective well-being. J Pers Soc Psychol. 1986;51:1058–68.
3. Emmons RA. Personal goals, life meaning, and virtue: Wellsprings of a positive life. In: Keyes CLM, Haidt J, editors. Flourishing: Positive psychology and the life well-lived. Washington: American Psychological Association; 2003. p. 105–28.
4. Little BR. Personal projects: a rationale and method for investigation. Environ Behav. 1983;15:273–309.
5. Locke EA, Shaw KN, Saari LM, Latham GP. Goal setting and task performance: 1969-1980. Psychol Bull. 1981;90:125–52.
6. Locke EA, Latham GP. Building a practically useful theory of goal setting and task motivation: A 35-year odyssey. Am Psychol. 2002;57:705–17.
7. Bandura A. Self-efficacy: Toward a unifying theory of behavioral change. Psychol Rev. 1977;84:191–215.
8. Ryan RM, Deci EL. Self-determination theory and the facilitation of intrinsic motivation, social development, and well-being. Am Psychol. 2000;55:68–78.
9. Carver CS, Scheier MF. On the Structure of Behavioral Self-Regulation. In: Boekaerts M, Zeidner M, Pintrich PR, editors. Handbook of Self-Regulation. 1st edition. Academic Press; 1999. p. 41–110.
10. Little B. Generative Contexts of Personal Projects Analysis. In: Little BR, Philips SD, Salmela-Aro K, editors. Personal project pursuit: goals, action, and human flourishing. Mahwah, N.J.: Lawrence Erlbaum Associations; 2007. p. 3–49.
11. Carver CS, Scheier MF. Control theory: A useful conceptual framework for personality–social, clinical, and health psychology. Psychol Bull. 1982;92:111–35.
12. Carver CS, Scheier MF. Principles of self-regulation: Action and emotion. In: Higgins ET, Sorrentino RM, editors. Handbook of motivation and cognition: Foundations of social behavior. New York, NY: The Guilford Press; 1990. p. 3–52.
13. Freund AM. Differentiating and integrating levels of goal representation: a life span perspective. In: Little BR, Philips SD, Salmela-Aro K, editors. Personal project pursuit: goals, action, and human flourishing. Mahwah, N.J.: Lawrence Erlbaum Associations; 2007. p. 247–70.
14. Klug HJP, Maier GW. Linking goal progress and subjective well-being: a meta-analysis. J Happiness Stud. 2015;16:37–65.
15. Sheldon KM, Kasser T. Goals, Congruence, and Positive Well-Being: New Empirical Support for Humanistic Theories. Nal Humanist Psychol. 2001;41:30–50.
16. Sheldon KM, Kasser T. Pursuing Personal Goals: Skills Enable Progress, but Not all Progress is Beneficial. Pers Soc Psychol Bull. 1998;24:1319–31.
17. Brunstein JC. Personal Goals and Subjective Well-Being: A Longitudinal Study. J Pers Soc Psychol. 1993;65(5):1061-1070.

18. Riediger M. Interference and facilitation among personal goals: age and associations with well-being and behavior. In: Little BR, Philips SD, Salmela-Aro K, editors. Personal project pursuit: goals, action, and human flourishing. Mahwah, N.J.: Lawrence Erlbaum Associations; 2007. p. 119–43.
19. Salmela-Aro K, Nurmi J-E, Saisto T, Halmesmäki E. Goal reconstruction and depressive symptoms during the transition to motherhood: Evidence from two cross-lagged longitudinal studies. J Pers Soc Psychol. 2001;81:1144–59.
20. Okun MA, Stock WA, Haring MJ, Witter RA. Health and Subjective Well-Being: A Meta-Analyis. Int J Aging Hum Dev. 1984;19:111–32.
21. Peterman A, Lecci L. Personal projects in health and illness. In: Little BR, Philips SD, Salmela-Aro K, editors. Personal project pursuit: goals, action, and human flourishing. Mahwah, N.J.: Lawrence Erlbaum Associations; 2007. p. 329–53.
22. Hullmann SE, Robb SL, Rand KL. Life goals in patients with cancer: a systematic review of the literature: Life goals in patients with cancer. Psychooncology. 2016;25:387–99.
23. Sulkers E, Janse M, Brinksma A, Roodbol PF, Kamps WA, Tissing WJE, et al. A longitudinal case–control study on goals in adolescents with cancer. Psychol Health. 2015;30:1075–87.
24. Canadian Cancer Statistics Advisory Committee. Canadian Cancer Statistics 2018. Toronto, ON: Canadian Cancer Society; 2018. cancer.ca/Canadian-Cancer-Statistics-2018-EN. Accessed 29 Jan 2019.
25. Bower JE. Behavioral Symptoms in Patients With Breast Cancer and Survivors. J Clin Oncol. 2008;26:768–77.
26. Hidding JT, Beurskens CHG, van der Wees PJ, van Laarhoven HWM, Nijhuis-van der Sanden MWG. Treatment Related Impairments in Arm and Shoulder in Patients with Breast Cancer: A Systematic Review. PLoS ONE. 2014;9:e96748.
27. Grimison PS, Stockler MR. Quality of life and adjuvant systemic therapy for early-stage breast cancer. Expert Rev Anticancer Ther. 2007;7:1123–34.
28. Burgess C, Cornelius V, Love S, Graham J, Richards M, Ramirez A. Depression and anxiety in women with early breast cancer: five year observational cohort study. BMJ. 2005;330:702.
29. Davis LE, Fulton C, Bubis LD, Sussman J, Moody L, Barbera L, et al. Patient-reported symptoms following mastectomy alone or lumpectomy plus radiation for early stage breast cancer: a cohort study. Breast Cancer Res Treat. 2019;175:721-31.
30. Epping-Jordan JE, Compas BE, Osowiecki DM, Oppedisano G, Gerhardt C, Primo K, et al. Psychological adjustment in breast cancer: Processes of emotional distress. Health Psychol. 1999;18:315–26.
31. Henselmans I, Helgeson VS, Seltman H, de Vries J, Sanderman R, Ranchor AV. Identification and prediction of distress trajectories in the first year after a breast cancer diagnosis. Health Psychol. 2010;29:160–8.
32. Montazeri A. Health-related quality of life in breast cancer patients: A bibliographic review of the literature from 1974 to 2007. J Exp Clin Cancer Res. 2008;27:32.
33. Stanton AL, Wiley JF, Krull JL, Crespi CM, Hammen C, Allen JJB, et al. Depressive episodes, symptoms, and trajectories in women recently diagnosed with breast cancer. Breast Cancer Res Treat. 2015;154:105–15.

34. Weisman AD, Worden JW. The existential plight in cancer: significance of the first 100 days. Psychiatry Med. 1976;7:1–15.

35. Zabora J, Brintzenhofeszoc K, Curbow B, Hooker C, Piantadosi S. The prevalence of psychological distress by cancer site. Psychooncology. 2001;10:19–28.

36. Maass SWMC, Roorda C, Berendsen AJ, Verhaak PFM, de Bock GH. The prevalence of long-term symptoms of depression and anxiety after breast cancer treatment: A systematic review. Maturitas. 2015;82:100–8.

37. Schmid-Büchi S, Halfens RJG, Müller M, Dassen T, van den Borne B. Factors associated with supportive care needs of patients under treatment for breast cancer. Eur J Oncol Nurs. 2013;17:22–9.

38. Institute of Medicine. Crossing the quality chasm: A new health system for the 21st century. Washington DC: National Academy Press; 2001. https://www.nap.edu/read/10027/chapter/2#5.

39. Ontario Medical Association. Ontario Medical Association - Policy On Patient-Centred Care. Ont Med Rev. 2010;34–49.

40. Greenlee H, Balneaves LG, Carlson LE, Cohen M, Deng G, Hershman D, et al. Clinical practice guidelines on the use of integrative therapies as supportive care in patients treated for breast cancer. JNCI Monogr. 2014;2014:346–58.

41. Rees L. Integrated medicine. BMJ. 2001;322:119–20.

42. Weeks LC, Seely D, Balneaves LG, Boon HS, Leis A, Oneschuk D, et al. Canadian integrative oncology research priorities: results of a consensus-building process. Curr Oncol. 2013;20:e289-299.

43. Wieland L, Manheimer E, Berman B. Development and classification of an operational definition of complementary and alternative medicine for the Cochrane Collaboration. Altern Ther Health Med. 2011;17:50–9.

44. Reuben DB, Tinetti ME. Goal-oriented patient care — an alternative health outcomes paradigm. N Engl J Med. 2012;366:777–9.

45. Verhoef MJ, Vanderheyden LC, Dryden T, Mallory D, Ware MA. Evaluating complementary and alternative medicine interventions: in search of appropriate patient-centered outcome measures. BMC Complement Altern Med. 2006;6.

46. Gagliese L, Jovellanos M, Zimmermann C, Shobbrook C, Warr D, Rodin G. Age-Related Patterns in Adaptation to Cancer Pain: A Mixed-Method Study. Pain Med. 2009;10:1050–61.

47. Stefanic N, Caputi P, Iverson DC. Investigating physical symptom burden and personal goal interference in early-stage breast cancer patients. Support Care Cancer. 2014;22:713–20.

48. Wrosch C, Scheier MF, Miller GE, Schulz R, Carver CS. Adaptive self-regulation of unattainable goals: goal disengagement, goal reengagement, and subjective well-being. Pers Soc Psychol Bull. 2003;29:1494–508.

49. Frenkel M, Cohen L, Peterson N, Palmer JL, Swint K, Bruera E. Integrative medicine consultation service in a comprehensive cancer center: findings and outcomes. Integr Cancer Ther. 2010;9:276–83.

50. Hack CC, Antoniadis S, Hackl J, Langemann H, Schwitulla J, Fasching PA, et al. Breast cancer patients' satisfaction with individual therapy goals and treatment in a standardized integrative medicine consultancy service. Arch Gynecol Obstet. 2018;298:147–56

Chapter 2: Personal goal-setting among women living with breast cancer: protocol for a scoping review (Manuscript #1)

Chow A, Presseau J, Perelman I, Sikora L, Fergusson D. Personal goal-setting among women living with breast cancer: protocol for a scoping review. Systematic Reviews. 2018;7:132.

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2.1 ABSTRACT

Background: Breast cancer and its treatment can have many physical and psychological effects on affected women. Women's personal goals may provide insight into their priorities and motivations in the context of breast cancer. Incorporating personal goal-setting into support and care interventions may have an effect on psychological well-being. This protocol describes our scoping review methods, the aim of which is to examine and map the existing evidence on personal goal-setting among women with a breast cancer diagnosis.

Methods: Our scoping review will search for published, full-length articles, where personal goal-setting is a major component of the study, and the study population is females with breast cancer. Medline, PsycInfo, CINAHL, Embase, and the Cochrane Library, and AMED databases will be searched. Two independent reviewers will conduct all screening and extract data. Descriptive information about the studies, participants, any interventions, measurement tools, outcomes and results will be reported.

Discussion: The results from this review will chart the literature, contributing to optimizing the incorporation of personal goal-setting approaches into effective interventions for the care and support of women with breast cancer.

Keywords

Goal-setting, personal goals, breast cancer, scoping review

2.2 BACKGROUND

Personal goals are an individual's cognitive expressions of desired states or processes which provide directional motivation towards a state,[1,2] i.e. they are something a person wants to aim for, maintain, or avoid. Everyday life is characterized by the pursuit of personal goals, such as normative goals (for example, "keep meeting my sister for lunch every Sunday") and self-defining idiosyncratic pursuits (for example, "read one biography every week"), combining to describe important expressions of life motivations.[3] *Personal goal setting* is the action of selecting or establishing personal goals, and provides motivation for further action towards pursuing goals.[1,4,5] The personal goals we set and pursue are influenced by individual and contextual factors, both stable and dynamic.[1,6] For example, individual traits such as extraversion and conscientiousness are predictors of the types of goals set by young adults.[7] The diagnosis of any cancer or serious illness can change the goals that people pursue by prompting the addition of new goals and the disengagement from existing goals, or by shifting a person's focus from extrinsic to more intrinsic (for example, health-related) goals.[8-10] Cancer and its treatment can also limit an individual's time and physical and mental energy to pursue personally important goals.[8,11] For instance, for women with breast cancer, treatment can have many side effects including fatigue, pain and physical limitations, premature menopause, and negative effects on cognitive functioning.[12-14] Women may also experience anxiety, distress, or mental health concerns as a result of the diagnosis and throughout the treatment. Indeed, a higher burden of breast cancer-related physical symptoms has been associated with a reduced ability to pursue goals and with psychological distress.[15] While generally the disruption of goal pursuit can reduce well-being and the ability to engage in new goals is positively associated with subjective well-being and better psychological outcomes,[16] the dynamics of such goal pursuit with a major life event such as breast cancer diagnosis and treatment is less clear. Supporting women with breast

cancer to set and pursue goals that are meaningful may result in outcomes that contribute to a higher quality of life. Stakeholders tasked with design and delivery of interventions and programs of care that can support women with their personal goal pursuit would benefit from greater clarity in how personal goal setting has been approached in this population. While a previous systematic review collated research on the life goals of people living with any type of cancer,[9] to our knowledge there is no assessment of the literature specifically focussed on goal-setting among women with breast cancer.

Women diagnosed with breast cancer face many challenges similar to people with a different cancer diagnosis, but they are also a unique population in several ways important to personal goal-setting and those developing support for them. Breast cancer overwhelmingly affects women. Gender, which is shaped by individual, social and cultural contexts, may predict some goals: women may tend to value goals for social harmony more than men, who tend to value economic achievement goals more than women.[7] Among younger women, cancer diagnoses are most likely to be of the breast than any other cancer.[17,18] In healthy populations, the content of personal goals tends to change with age, and perceived control over health goals decreases with age.[19,20] Because breast cancer affects more younger women than other cancers, illness and age may potentially influence differences in personal goal selection and factors associated with their pursuit. Furthermore, this is an active area of research and we have informally identified several additional studies on the goals of women with breast cancer published since Hullmann et al conducted the search for their study in 2014.[21-27]

In this protocol, we present our methods for conducting a scoping review. The objective of our scoping review is to examine and map the existing literature on personal goal-setting among women with a breast cancer diagnosis, with the aim to address four research questions:

(1) How many studies have examined personal goal-setting among women with breast cancer and what were the characteristics of these studies?

(2) In studies that involved goal-setting as part of an intervention, what were the characteristics of the interventions used in these studies; what comprised the intervention, who delivered the intervention, and when, where, and how was the intervention delivered?

(3) What instruments were used in these interventions to elicit and evaluate the personal goals of women with breast cancer?

(4) What were the primary results of the studies that have used validated instruments?

2.3 METHODS

This protocol was developed following guidelines for planning and conducting systematic and scoping reviews recommended by the Joanna Briggs Institute and the Cochrane Collaboration.[28-31] A completed PRISMA-P checklist is presented in Appendix 1. This protocol is not registered on PROSPERO.

2.3.1 Search strategy

To minimize missed studies and bias, several electronic databases will be searched, from inception to the present day: MEDLINE (OVID interface); PsycINFO (OVID interface); EMBASE (OVID interface); CINAHL (Ebsco interface); AMED (OVID interface); and the Cochrane Library (Ovid interface, composed of seven databases: Cochrane Database of Systematic Reviews; ACP Journal Club; Database of Abstracts of Reviews of Effects, current issue; Cochrane Central Register of Controlled Trials, current issue; Cochrane Methodology Register, current issue; Health Technology Assessment, current issue; and NHS Economic Evaluation Database, current issue).

The trials register, clinicaltrials.gov, will be searched for additional trials. To ensure literature saturation, the reference lists of included studies and relevant reviews identified through the search will be scanned for further citations. Any relevant conference abstracts identified in the search will be highlighted for keywords and electronic databases and Google Scholar will be searched to identify any full-length articles related to the abstract. Other grey literature will not be searched.

To identify published literature, this review will employ a strategy guided by recommendations from the Joanna Briggs Institute Reviewers Manual and the Cochrane Collaboration.[28-31] Literature search strategies were developed using medical subject headings (MeSH) and text key words related to breast cancer, goals, and goal-setting adapted from a systematic review on goal-setting in rehabilitation.[32] The outcomes will not be restricted in the search strategy. A literature search strategy for Medline was developed with the aid of a health sciences librarian with experience in scoping review searching, Lindsey Sikora (LS). A draft of the Medline strategy is outlined in Appendix 2. This strategy, once finalized, will be adapted to the syntax and subject headings of the other databases by AC and checked by LS. After articles are screened for inclusion in two stages, the reference list of all included papers will be searched for additional studies.

No study design, publication status, date or language limits will be imposed on the search, although only studies in English will be eligible for inclusion, due to resource limits. Although conference abstracts, theses and dissertations will not be included in our review as outlined in the eligibility criteria below, they will be searched for to ensure literature saturation as described above. Databases will be searched for articles published at any time up until June 2017 (up until and including the date of the initial search).

2.3.2 Data management

Literature search results will be uploaded to and merged using Endnote X7 software. Inclusion and exclusion of citation abstracts in stage 1 screening, and articles at Stage 2 screening will be tracked using *Covidence*.

2.3.3 Selection process

Two reviewers will conduct a two-stage screening process to minimize bias and errors, and increase rigor. After the literature search is conducted and duplicates removed, two reviewers will independently and in duplicate screen the titles and abstracts identified in the search strategy detailed above. Each title will be screened using a screening guide. Titles will be retained if they appear to meet the inclusion criteria of if it is uncertain if they do.

Full-text articles will be obtained for all titles retained from stage 1 screening. If a full-text article (excluding conference abstracts) from an electronic database cannot be located online, the study authors will be contacted to request a copy of the article. A maximum of two email attempts over two weeks will be made. If an article cannot be obtained from the authors, or must be purchased to be obtained, it will be excluded and the reason documented. If the text of a conference abstract cannot be obtained online, a related full-length article will not be searched for. For all grey literature, including theses or dissertations, if the full-text article cannot be located online, the citation will be excluded and the reason documented. At stage 2 screening, two reviewers will independently and in duplicate screen all full-text articles, examining them for compliance with the eligibility criteria of this review. Disagreements will be resolved through discussion. If agreement cannot be made, a third party (DF or JP) will arbitrate.

To avoid inclusion of duplicate publications of the same study, the list of included studies at stage 2 screening will be examined for: the same author names, locations or settings, interventions, number of participants, study dates, and study duration. If duplicate publications

are identified, they will be removed from the list of included studies.

2.3.4 Eligibility Criteria

Inclusion and exclusion criteria are summarized in Table 1.

Types of study design

Primary studies of any design (e.g. experimental, observational, qualitative, cross-sectional, etc) will be included. A broad range of studies is desired to meet this review's scoping objective. Studies where the primary purpose was to develop or validate an outcome measurement tool will be included, as this study is interested in identifying instruments used to set and evaluate participants' personal goals. Systematic reviews will be excluded.

Types of participants

This review will include studies involving participants who had ever received a diagnosis of breast cancer, regardless of time since diagnosis. Survivorship is considered a phase in the cancer experience, and cancer recurrence and mortality remain a possibility and fear. Only the female sex will be included; males will be excluded. Participants may be of any age. Any breast cancer stage or severity will be included. Women at any stage (planning, undergoing, completed) of any cancer treatment (chemotherapy, radiation, surgery, alternative therapies) will be included. Women who have decided not to pursue cancer treatment (for example, because of personal beliefs, or because their care is palliative) will be included. They can still access cancer care and support and therefore understanding participant involvement in goal-setting is relevant to this population. Studies that include other cancer sites (for example, prostate, lung, etc) will be included if data on the outcomes for women with breast cancer can be extracted. Otherwise, studies where breast cancer is one of multiple cancer sites studied will be excluded.

Types of intervention

For studies identified that include the description of an intervention being evaluated, such interventions of all included studies must include either the identification of participants' existing personal goals or the setting of new goals for the participant as a major component of the intervention. To be a major component, the article's introduction should present a justification or theoretical basis for how goal-setting is expected to affect the outcome. Studies where goal-setting is not a major component of the intervention will be excluded. Studies examining personal goal-setting in any life domain (e.g. relationships, occupational, or health) will be included. Studies which examine organizational or group goal interventions, participant preferences (where participants select or rank goals from a provided list), or life values will be excluded. In studies involving the evaluation of interventions where the intervention involves setting new personal goals, studies that involve participants in goal-setting, either by having participants set the goals or having them set the goals jointly with someone else (e.g. a health worker or practitioner, a family member, researcher) will be included. Studies in which someone other than the participant (e.g. study researchers, health professionals) provides parameters for goals (e.g. goals for treatment, goals over the next month) will be included, as long as the participant is involved in setting the actual goals. Although goals for treatment may be elicited in order to inform treatment plans, we include them because they may become a part of an individual's personal goal system[33] due to the nature of a cancer diagnosis and journey. Studies where goals are set by someone other than the participant without their involvement, or where someone other than the participant sets or recommends an overall goal, followed by participant involvement in setting smaller, intermediate goals towards the overall goal, will be excluded. In studies where the intervention/exposure involves setting new personal goals, the personal goals set must be articulated, either verbally or written during the intervention. Studies that only

encourage or provide training or support for personal goal-setting, without setting personal goals in the study, will be excluded.

Types of outcomes

All outcomes reported will be included in the review. Measures can be subjective (e.g. sleep loss reported by the participant) or objective (e.g. sleep loss measured by sleep monitor). This review will distinguish primary outcomes of a reported study from other outcomes.

Language

Only studies published in English will be included, due to the linguistic abilities of the reviewers. Studies in any other language will be excluded.

Publication status

Only published, full-length articles will be included. Commentaries, letters, books, review articles, theses, dissertations, and conference abstracts will be excluded.

Other

There will be no restrictions on date of study or length of follow-up time. All clinical and non-clinical settings (for example, home care, community institutions) will be included. Care of women with cancer does not take place exclusively in a clinical setting, and comprehensive evidence of interventions is desired.

2.3.5 Data Extraction

This review will record key information from included articles in a Microsoft Excel data extraction form designed *a priori*. Two reviewers will independently extract data to minimize errors. The data abstraction form will be piloted to reduce potential errors in collecting data and determine if the form extracts the desired data. AC will review the objectives, methods, results and discussion section of each article to identify any important information not extracted. The

form will then be refined, re-piloted, and finalized, and then full data extraction conducted. Any modifications to the form will be documented in the final report.

If an article is missing information about the intervention, outcomes or results, this will be noted in the data extraction. No data will be imputed. If duplicate publications are identified during data collection, they will be removed. If there are multiple reports from a single study, data from the study will be collated either by extracting data from each study separately and then combining the information from multiple data abstraction forms, or extracting data from all articles into one single data abstraction form, depending on the form of each article.

2.3.6 Data items

Planned variables to be extracted in this review are outlined in Table 2 (subject to change, key information will be identified in an iterative process). Data extracted will include: participant information, study information, methodology, intervention/exposure details, outcome measures, and all reported results.

The TIDieR checklist will be used to guide extraction of data about interventions.[34] We will extract information on goal-setting processes in study interventions, including their justification. For interventions which set new personal goals, intervention descriptions will be extracted as described in the papers, then characterized by coding using the Goals and Planning category (cluster 1) of the Behavior Change Technique Taxonomy,[35] a classification system of behavior change techniques. We will also extract information on intervention techniques to support participants to successfully pursue their goals, and the validity of instruments used to identify and rate personal goals. We expect that, where validation has occurred, we will find evidence of construct validity and potentially concurrent validity. Given the individualized nature of goal-setting, we do not expect to find evidence of criterion validity. We plan to extract information on the populations with which identified instruments have been validated.

2.3.7 Data synthesis

The number of studies identified and selected at each stage of the scoping review, along with the number of articles excluded at level 1 and 2 screening, and the reasons for exclusion at level 2 screening, will be presented in a PRISMA flow diagram.[32] Results will be summarized in table form, and discussed in more depth in narrative form to address each of the four research questions. Results will be grouped conceptually, by study characteristics, participant characteristics, study objectives, intervention/exposure (if applicable), instruments used to identify personal goals, outcomes measured and time points, and results. This review will present summaries of these categories, with a particular focus on studies' interventions or exposures, goal-setting techniques, including whether studies defined parameters for goals, and reported results, including quantitative measurements of associations (mean differences for scores by validated questionnaires, risk ratios or odds ratios for dichotomous outcomes) if applicable. Additional groups may be identified during the extraction of results.

2.4 DISCUSSION

By charting the literature on personal goal-setting among women with breast cancer, the results from this scoping review will contribute aggregated knowledge on the personal goals of women with breast cancer that can help to identify personal motivations that are important to individual women. This knowledge can be helpful for the development of new interventions or the optimization of existing ones, as part of appropriate treatment and care plans for women with breast cancer and survivors. Such care could help women to shift or adapt new goals to facilitate the likelihood of successful goal pursuit, improve psychological outcomes, and improve experiences of cancer care and treatment.

List of abbreviations

BCT: Behavior Change Taxonomy

PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analyses

TIDieR: Template for Intervention Description and Replication

Declarations

Ethics approval and consent to participate

Not applicable

Consent for publication

Not applicable

Availability of data and materials

Not applicable

Competing interests

The authors declare that they have no competing interests.

Acknowledgements

None.

Funding

No funding was received for this project.

Authors' contributions

AC planned the study, drafted the protocol, conducted data analysis, and wrote the manuscript. DF and JP provided content and methodological expertise, and commented on the drafts of the protocol. LS and AC designed the search strategy. AC and IP conducted the screening and data extraction. All authors read and approved the final manuscript.

2.5 TABLES

List of Tables

Table 1. Eligibility criteria

	Inclusion	Exclusion
Study design	Primary studies of any design	Systematic reviews
ɔpulation	Females with a diagnosis of breast cancer	Males, studies where multiple cancers are studied and outcome data for women with breast cancer cannot be extracted
Intervention/ exposure	Examines personal goal-setting as major component of the intervention; involves the participant in setting goals	Personal goal-setting is not a major intervention component; examines organizational/ group goals, participant preferences or life values; does not involve the participant in setting goals
Outcomes	All outcomes	n/a
Language	English	Anything other than English
Publication status	Published, full-length articles	Commentaries, letters, books, review articles, conference abstracts, theses or dissertations
Other	All study dates, length of follow-up, setting	n/a

Table 2. Planned variables to be extracted in the scoping review

General study details	Study ID number, lead author, title, journal, year of publication, type of publication, information source, primary and secondary purposes
Study characteristics	Study design, study duration, pilot/feasibility study (y/n), number of study arms, covariates (definition and measurement methods)
Participants	Total number, setting, inclusion and exclusion criteria Participant characteristics at baseline: for each study, average age (years, mean and standard deviation [SD]), sex (%), country, cancer treatment received, breast cancer treatment stage, time since diagnosis (or time since treatment, if treatment was completed) *If available:* breast cancer stage, race or ethnicity, socioeconomic status
Interventions /exposures and comparators	Total number of intervention/exposure and comparison groups, number of participants in each group For each intervention/exposure and comparison group: justification for goal-setting, type of goal setting used (BCT), materials and procedures used, who administered the intervention/exposure/comparison, training to deliver goal-setting, mode of delivery, location, timing of delivery, duration of intervention/exposure, any tailoring of the intervention, any modifications, techniques to support goal pursuit, co-interventions (if any), intervention adherence or fidelity – who and how assessed, and results of assessment For each intervention/exposure: participant involvement in personal goal-setting, new or existing goals identified, any parameters given for goal-setting. For each comparison (if applicable): whether personal goal-setting was part of the intervention, participant involvement (if any) if goals were set
Instruments used in goal-setting	Type of instrument used, construct validity (if reported), concurrent validity (if reported), validated with women with breast cancer, feasibility (if reported)
Outcomes	List of outcomes and time points a) collected, b) reported. Identification of study's primary outcome Data collection method: quantitative or qualitative For each outcome: outcome definition (narrative plus name of scale or diagnostic method) For scales: validity, upper and lower limits, direction of benefit
Results	For each quantitative outcome: sample size, number of missing participants, reasons for loss to follow up, summary data for each group (2x2 table for dichotomous data, means and SDs for continuous data), estimate of effect for difference between groups (or change in baseline and final scores for single-arm studies), confidence intervals, p-value

2.6 REFERENCES FOR CHAPTER 2

1. Austin JT, Vancouver JB. Goal constructs in psychology: Structure, process, and content. Psychol Bull. 1996;120:338–75.

2. Elliot A, Thrash T. Achievement goals and the hierarchical model of achievement motivation. Educ Psychol Rev. 2001;13:139–56.

3. Ryan RM, Deci EL. Self-determination theory and the facilitation of intrinsic motivation, social development, and well-being. Am Psychol. 2000;55:68–78.

4. Locke EA, Shaw KN, Saari LM, Latham GP. Goal setting and task performance: 1969-1980. Psychol Bull. 1981;90:125–52.

5. Scobbie L, Dixon D, Wyke S. Goal setting and action planning in the rehabilitation setting: development of a theoretically informed practice framework. Clin Rehabil. 2011;25:468–82.

6. Little B. Generative Contexts of Personal Projects Analysis. In: Little BR, Philips SD, Salmela-Aro K, editors. Personal project pursuit: goals, action, and human flourishing. Mahwah, N.J.: Lawrence Erlbaum Associations; 2007. p. 3–49.

7. Roberts BW, Robins RW. Broad Dispositions, Broad Aspirations: The Intersection of Personality Traits and Major Life Goals. Pers Soc Psychol Bull. 2000;26:1284–96.

8. Peterman A, Lecci L. Personal projects in health and illness. In: Little BR, Philips SD, Salmela-Aro K, editors. Personal project pursuit: goals, action, and human flourishing. Mahwah, N.J.: Lawrence Erlbaum Associations; 2007. p. 329–53.

9. Hullmann SE, Robb SL, Rand KL. Life goals in patients with cancer: a systematic review of the literature: Life goals in patients with cancer. Psychooncology. 2016;25:387–99.

10. Sulkers E, Janse M, Brinksma A, Roodbol PF, Kamps WA, Tissing WJE, et al. A longitudinal case–control study on goals in adolescents with cancer. Psychol Health. 2015;30:1075–87.

11. Gagliese L, Jovellanos M, Zimmermann C, Shobbrook C, Warr D, Rodin G. Age-Related Patterns in Adaptation to Cancer Pain: A Mixed-Method Study. Pain Med. 2009;10:1050–61.

12. Bower JE. Behavioral Symptoms in Patients With Breast Cancer and Survivors. J Clin Oncol. 2008;26:768–77.

13. Hidding JT, Beurskens CHG, van der Wees PJ, van Laarhoven HWM, Nijhuis-van der Sanden MWG. Treatment Related Impairments in Arm and Shoulder in Patients with Breast Cancer: A Systematic Review. PLoS ONE. 2014;9:e96748.

14. Grimison PS, Stockler MR. Quality of life and adjuvant systemic therapy for early-stage breast cancer. Expert Rev Anticancer Ther. 2007;7:1123–34.

15. National Cancer Institute. Adjustment to cancer: anxiety and distress (PDQ). Health professional version. Overview. 2014. https://www.cancer.gov/about-cancer/coping/feelings/anxiety-distress-hp-pdq. Accessed 3 Mar 2017.

16. Stefanic N, Caputi P, Iverson DC. Investigating physical symptom burden and personal goal interference in early-stage breast cancer patients. Support Care Cancer. 2014;22:713–20.

17. Wrosch C, Scheier MF, Miller GE, Schulz R, Carver CS. Adaptive self-regulation of unattainable goals: goal disengagement, goal reengagement, and subjective well-being. Pers Soc Psychol Bull. 2003;29:1494–508.

18. Canadian Cancer Society's Committee on Cancer Statistics. Canadian Cancer Statistics 2016. Toronto, ON: Canadian Cancer Society; 2016.

19. National Cancer Institute. Cancer Statistics Interactive Tools. Surveillance, Epidemiology, and End Results Program. https://seer.cancer.gov/statistics/intteractive.html. Accessed 13 Feb 2018.

20. Nurmi J-E, Pulliainen H, Salmela-Aro K. Age differences in adults' control beliefs related to life goals and concerns. Psychol Aging. 1992;7:194–6.

21. Nurmi J-E. Age Differences in Adult Life Goals, Concerns, and Their Temporal Extension: A Life Course Approach to Future-oriented Motivation. Int J Behav Dev. 1992;15:487–508.

22. Lam WWT, Yeo W, Suen J, Ho WM, Tsang J, Soong I, et al. Goal adjustment influence on psychological well-being following advanced breast cancer diagnosis: Goal adjustment and psychological well-being. Psychooncology. 2016;25:58–65.

23. Low CA, Stanton AL. Activity disruption and depressive symptoms in women living with metastatic breast cancer. Health Psychol. 2015;34:89–92.

24. Mens MG, Scheier MF. The Benefits of Goal Adjustment Capacities for Well-Being Among Women With Breast Cancer: Potential Mechanisms of Action: Goal Adjustment, Well-Being, and Breast Cancer. J Pers. 2016;84:777–88.

25. Ng AV, Cybulski AN, Engel AA, Papanek PE, Sheffer MA, Waltke LJ, et al. Triathlon training for women breast cancer survivors: feasibility and initial efficacy. Support Care Cancer. 2016;25:1465-73.

26. Otto AK, Szczesny EC, Soriano EC, Laurenceau J-P, Siegel SD. Effects of a randomized gratitude intervention on death-related fear of recurrence in breast cancer survivors. Health Psychol. 2016;35:1320–8.

27. Stefanic N, Iverson DC, Caputi P, Lane L. Examining the influence of personal goal interference and attainability on psychological distress in non-metastatic breast cancer patients. Eur J Cancer Care (Engl). 2016. doi:10.1111/ecc.12494.

28. Xia H-Z, Gao L, Yue H, Shi B-X. Exploring Meaning in the Life of Chinese Breast Cancer Survivors: Cancer Nurs. 2016;:1.

29. Peters M, Godfrey C, McInerney P, Soares C, Hanan K, Parker D. The Joanna Briggs Institute Reviewers' Manual 2015: Methodology for JBI Scoping Reviews. Adelaide, Australia: The Joanna Briggs Institute; 2015.

30. Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group. Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med. 2009;6:e1000097.

31. Shamseer L, Moher D, Clarke M, Ghersi D, Liberati A, Petticrew M, et al. Preferred reporting items for systematic review and meta-analysis protocols (PRISMA-P) 2015: elaboration and explanation. BMJ. 2015;349 jan02 1:g7647–g7647.

32. Higgins JPT, Green S, Cochrane Collaboration, editors. Cochrane handbook for systematic reviews of interventions. Chichester, England ; Hoboken, NJ: Wiley-Blackwell; 2008.

33. Levack WM, Weatherall M, Hay-Smith EJC, Dean SG, McPherson K, Siegert RJ. Goal setting and strategies to enhance goal pursuit for adults with acquired disability participating in rehabilitation. In: The Cochrane Collaboration, editor. Cochrane Database of Systematic Reviews. Chichester, UK: John Wiley & Sons, Ltd; 2015. doi:10.1002/14651858.CD009727.pub2.

34. Michalak J, Holtforth MG. Where Do We Go From Here? The Goal Perspective in Psychotherapy. Clin Psychol Sci Pract. 2006;13:346–65.

35. Hoffmann TC, Glasziou PP, Boutron I, Milne R, Perera R, Moher D, et al. Better reporting of interventions: template for intervention description and replication (TIDieR) checklist and guide. BMJ. 2014;348 mar07 3:g1687–g1687.

36. Michie S, Richardson M, Johnston M, Abraham C, Francis J, Hardeman W, et al. The Behavior Change Technique Taxonomy (v1) of 93 Hierarchically Clustered Techniques: Building an International Consensus for the Reporting of Behavior Change Interventions. Ann Behav Med. 2013;46:81–95.

Appendix 1 - **PRISMA-P checklist**

Section/topic	#	Checklist item	Information reported		Line number(s)
			Yes	No	
ADMINISTRATIVE INFORMATION					
Title					
Identification	1a	Identify the report as a protocol of a systematic review	☒	☐	103
Update	1b	If the protocol is for an update of a previous systematic review, identify as such	☐	☐	n/a
Registration	2	If registered, provide the name of the registry (e.g. PROSPERO) and registration number in the Abstract	☒	☐	n/a
Authors					
Contact	3a	Provide name, institutional affiliation, and e-mail address of all protocol authors; provide physical mailing address of corresponding author	☒	☐	4 - 23
Contributions	3b	Describe contributions of protocol authors and identify the guarantor of the review	☒	☐	329 - 333
Amendments	4	If the protocol represents an amendment of a previously completed or published protocol, identify as such and list changes; otherwise, state plan for documenting important protocol amendments	☐	☐	n/a
Support					
Sources	5a	Indicate sources of financial or other support for the review	☒	☐	326 - 328
Sponsor	5b	Provide name for the review funder and/or sponsor	☐	☐	n/a
Role of sponsor/funder	5c	Describe roles of funder(s), sponsor(s), and/or institution(s), if any, in developing the protocol	☐	☐	n/a
INTRODUCTION					
Rationale	6	Describe the rationale for the review in the context of what is already known	☒	☐	52 – 101
Objectives	7	Provide an explicit statement of the question(s) the review will address with reference to participants, interventions, comparators, and outcomes (PICO)	☒	☐	103-113
METHODS					
Eligibility criteria	8	Specify the study characteristics (e.g. PICO, study design, setting, time frame) and report characteristics (e.g. years considered, language, publication status) to be used as criteria for eligibility for the review	☒	☐	187 - 246
Information sources	9	Describe all intended information sources (e.g. electronic databases, contact with study authors, trial registers, or other grey literature sources) with planned dates of coverage	☒	☐	123-137, 147 - 149

Section/topic	#	Checklist item	Information reported		Line number(s)
			Yes	No	
Search strategy	10	Present draft of search strategy to be used for at least one electronic database, including planned limits, such that it could be repeated	☒	☐	Appendix 2
STUDY RECORDS					
Data management	11a	Describe the mechanism(s) that will be used to manage records and data throughout the review	☒	☐	158 - 161
Selection process	11b	State the process that will be used for selecting studies (e.g. two independent reviewers) through each phase of the review (i.e. screening, eligibility, and inclusion in meta-analysis)	☒	☐	163 - 185
Data collection process	11c	Describe planned method of extracting data from reports (e.g. piloting forms, done independently, in duplicate), any processes for obtaining and confirming data from investigators	☒	☐	248 - 262
Data items	12	List and define all variables for which data will be sought (e.g. PICO items, funding sources), any pre-planned data assumptions and simplifications	☒	☐	264 - 280
Outcomes and prioritization	13	List and define all outcomes for which data will be sought, including prioritization of main and additional outcomes, with rationale	☒	☐	232 - 235
Risk of bias in individual studies	14	Describe anticipated methods for assessing risk of bias of individual studies, including whether this will be done at the outcome or study level, or both; state how this information will be used in data synthesis	☐	☐	n/a
DATA					
Synthesis	15a	Describe criteria under which study data will be quantitatively synthesized	☐	☐	n/a
	15b	If data are appropriate for quantitative synthesis, describe planned summary measures, methods of handling data, and methods of combining data from studies, including any planned exploration of consistency (e.g. I^2, Kendall's tau)	☐	☐	n/a
	15c	Describe any proposed additional analyses (e.g. sensitivity or subgroup analyses, meta-regression)	☐	☐	n/a
	15d	If quantitative synthesis is not appropriate, describe the type of summary planned	☒	☐	282 - 294
Meta-bias(es)	16	Specify any planned assessment of meta-bias(es) (e.g. publication bias across studies, selective reporting within studies)	☐	☐	n/a
Confidence in cumulative evidence	17	Describe how the strength of the body of evidence will be assessed (e.g. GRADE)	☐	☐	n/a

Appendix 2 - Medline Search Strategy

1	exp Breast Neoplasms/
2	(breast adj3 cancer*).tw.
3	(breast adj3 carcinoma*).tw.
4	(breast adj3 neoplasm*).tw.
5	(breast adj3 tumo?r*).tw.
6	(mammar* adj3 cancer*).tw.
7	(mammar* adj3 carcinoma*).tw.
8	(mammar* adj3 neoplasm*).tw.
9	1 or 2 or 3 or 4 or 5 or 6 or 7 or 8
10	goals/ or intention/
11	(personal adj1 (project* or striving* or goal*)).tw.
12	(current adj1 concern*).tw.
13	(life adj1 task*).tw.
14	(goal* adj5 (set* or establish* or plan* or elicit* or agree* or negotiat* or propos* or develop* or formulat* or elaborat* or identif* or write or written or stat* or specif* or construct* or manag* or direct* or orient* or attain* or achiev* or evalua*)).tw.
15	(set* adj2 target*).tw.
16	(goal* adj1 (set* or plan* or attain* or direct* or orient* or cent?r* or assess* or adher* or complian*)).tw.
17	10 or 11 or 12 or 13 or 14 or 15 or 16
18	9 and 17

Chapter 3: Personal goal-setting among women living with breast cancer: a scoping review (Manuscript #2)

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3.1 PREFACE

This manuscript has not yet been submitted for publication.

3.2 ABSTRACT

Background: Personal goals provide motivation in everyday life and may have an impact on an individual's well-being. Breast cancer can disrupt the setting and pursuit of a woman's personal goals. Designing supports for women to set and pursue meaningful goals requires an understanding of the personal goals of women with breast cancer. This scoping review aimed to chart the existing evidence on personal goal-setting among women with a breast cancer diagnosis, specifically: 1) the number and characteristics of published studies examining personal goal-setting among women with breast cancer; 2) the characteristics of any study interventions involving personal goal-setting; 3) the instruments used to elicit and evaluate personal goals; and 4) the primary results of included studies.

Methods: We searched Medline, PsycINFO, CINAHL, Embase, the Cochrane Library, and AMED databases for published, full-length articles where personal goal-setting was a major component of the study and the study population was females with breast cancer. Two reviewers conducted all screening and extracted pre-specified information about the study designs, participants, interventions, measurement tools, outcomes and results.

Results: The literature search generated 5,187 citations. Twelve studies were included. Study designs varied, and seven of the studies were pilot or feasibility studies. Eight studies included an intervention and completeness of reporting intervention elements varied widely. Half used author-developed instruments to elicit personal goals; none of the studies used validated instruments.

Conclusion: A small number of published studies have examined personal goal-setting among women with breast cancer, with significant variability in study design and participant and intervention characteristics. Our findings indicate gaps in the evidence base, particularly in consistency of methods to set goals or elicit existing goals. Improved reporting of interventions is needed for effective implementation of those interventions in clinical settings and for accurate replication in further research.

Keywords

Goal-setting, personal goals, breast cancer, scoping review

3.3 BACKGROUND

Ideally, breast cancer care is concerned with providing meaningful support to women with breast cancer. Increasingly, meaningful support has come to encompass the provision of patient-centred care and focusing on the needs and outcomes important to women. Personal goals are cognitive expressions of an individual's desired states or processes that provide directional motivation; personal goals are what a person is aiming to achieve, maintain or avoid.[1,2] Everyday life is characterized by the pursuit of personal goals, including common, normative goals (for example, "keep meeting my sister for lunch every Sunday") and self-defining idiosyncratic pursuits (for example, "read one biography every week"), which combine to describe important expressions of life motivations.[3] Personal goal-setting is the action of selecting or establishing personal goals, and provides motivation for further action towards pursuing goals.[1,4,5] Personal goal-setting is associated with both successful goal pursuit and well-being.[3,6-12] A consideration of personal goals may be useful for interventions taking a patient-centred approach to care for women with breast cancer. Major health events such as the diagnosis of cancer or serious illness can affect the types of goals set and goal pursuit. A cancer diagnosis can change the goals that

people pursue through the addition of new goals and disengaging from existing ones, or by shifting a person's focus and priority of goals such as from extrinsic to more intrinsic (i.e. health-related) goals.[13-15] A diagnosis of cancer and its associated treatments add new constraints to an individual's time and physical and mental energy to pursue personally important goals.[13,16] A higher burden of breast cancer-related physical symptoms has been associated with a reduced ability to pursue goals and psychological distress.[17] The hindrance of goal pursuit among people with cancer is associated with negative well-being.[18] Stakeholders tasked with the design and delivery of interventions and programs of care for women with breast cancer would benefit from greater clarity about the personal goals set by this population. While a previous systematic review collated research on the life goals of people living with any type of cancer,[20] to our knowledge there is no assessment of the literature specifically focused on personal goal-setting among women with breast cancer.

Women diagnosed with breast cancer face challenges similar to people with other cancer diagnoses, yet they have unique characteristics relevant to personal goal-setting. Breast cancer overwhelmingly affects women; gender, which is shaped by individual, social and cultural contexts, may be predictive of some goals. For example, women may tend to value goals related to social harmony more than men, who may tend to value economic achievement goals more than women.[19] Among younger women, a cancer diagnosis is most likely to be of the breast than any other cancer.[20,21] In healthy populations, the content of personal goals tends to change with age, and perceived control over health goals decreases with age.[22,23] Because breast cancer affects younger women more than other cancers, illness and age may potentially influence differences in personal goal selection and factors associated with their pursuit. This is an active area of research and several articles have been published since Hullmann and colleagues conducted their 2014 search.[24-30]

The purpose of our scoping review was to examine and map the existing literature on personal goal-setting among women with a breast cancer diagnosis to address four research questions:

(1) How many published studies have examined personal goal-setting among women with breast cancer and what were the characteristics of these studies?

(2) In studies that involved goal-setting as part of an intervention, what were the characteristics of the intervention used in each study, what comprised the intervention, who delivered the intervention, and when, where, and how was the intervention delivered?

(3) What instrument was used in each intervention to elicit and evaluate the personal goals of women with breast cancer?

(4) What were the primary results of the studies that used validated instruments?

We used the general term "interventions" to cover existing organizational programs or projects as well as interventions conducted specifically within a research context. These interventions may have aimed to elicit personal goals or to elicit a change in a health-related outcome.

3.4 METHODS

We used the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) Checklist to guide our reporting[31] and conducted the review according to a pre-specified protocol.[32] Two main amendments were subsequently made to the protocol. In the inclusion criteria outlined in the original protocol, personal goal-setting was considered only as an element of study interventions. We amended the protocol to include studies where any key study variable (outcome, theme in qualitative studies, effect modifier or confounding variable)

involved personal goal-setting, and to exclude clinical guidelines and case studies. A full list of protocol amendments is presented in Appendix 1.

3.4.1 Search strategy

We searched several electronic databases from inception to June 19, 2017: MEDLINE (OVID interface); PsycINFO (OVID interface); EMBASE (OVID interface); CINAHL (Ebsco interface); AMED (OVID interface); and the Cochrane Library (OVID interface). Clinicaltrials.gov was searched on June 28, 2017 for additional trials and we searched the original electronic databases for study articles related to titles identified from clinicaltrials.gov.

To identify published literature, search strategies were developed using medical subject headings (MeSH) and key words related to breast cancer and goal-setting adapted from a systematic review on goal-setting in rehabilitation.[33] Outcomes were not restricted in the search. A health sciences librarian with experience in scoping review literature searches (LS) and the lead author (AC) developed a literature search strategy for Medline (see Chapter 2, Appendix 2). This strategy was then adapted to the syntax and subject headings of the other databases and clinicaltrials.gov by AC and checked by LS.

During screening, we flagged relevant conference abstracts and searched the original electronic databases and Google Scholar to identify full-length articles related to the abstracts. After screening, we scanned the reference list of all included studies and relevant reviews identified through the search for additional studies that might meet our inclusion criteria.

No search limits were imposed for study design, publication status, publication date or language. Although articles in languages other than English, conference abstracts, theses and dissertations were not eligible for inclusion, as outlined in the eligibility criteria below, they were included in the search to ensure literature saturation.

3.4.2 Study selection

Following the search and deduplication of records, two reviewers independently screened the identified titles and abstracts in duplicate. Each record was screened using the author-created Stage 1 screening guide. Records were retained if they appeared to meet the inclusion criteria or if it was uncertain if they did.

Full-text articles were obtained for all records retained from Stage 1. If a full-text article (excluding conference abstracts) could not be located or had to be purchased, the study authors were contacted by e-mail. Up to two contact attempts were made. If an article could not be obtained from the authors, it was excluded. If the text of a conference abstract could not be obtained online, we did not search further for a related full-length article. At Stage 2 screening, two reviewers (AC, IP) independently screened all full-text articles in duplicate, using the eligibility criteria. Reviewers followed the Stage 2 screening guide. Disagreements were resolved through discussion. If agreement could not be made, a third party (DF or JP) arbitrated.

If both Stage 2 reviewers agreed that a full-text article did not include enough information about the participants, methods, interventions, or inclusion of personal goal-setting to make a decision about inclusion or exclusion, the study authors were contacted to request more information. Up to two email attempts over two weeks were made. If the necessary information could not be obtained, the study was excluded. Literature search results were merged using Endnote X7 software.[34] Inclusion and exclusion of records during both screening stages were tracked using Covidence.[35]

3.4.3 Eligibility Criteria

Inclusion and exclusion criteria are summarized in Table 1.

Types of study design

A broad range of studies were included to meet this review's objective. Primary studies of any design (e.g. experimental, observational, qualitative, cross-sectional) except case studies were included. Studies where the primary purpose was to develop or validate an outcome measurement tool related to personal goal-setting were included.

Types of participants

We included studies involving females who had ever received a diagnosis of breast cancer, regardless of time since diagnosis, our rationale being that the experience of breast cancer continues to affect physical and psychological outcomes throughout survivorship. Females of all ages were included. Females with any stage or severity of breast cancer, and at any point (planning, undergoing, completed) of cancer treatment (chemotherapy, radiation, surgery or hormone treatment) were included. Women who had decided not to pursue cancer treatment (for example, because of personal beliefs, or because their care was palliative) were included. Studies where females with breast cancer were one of multiple populations studied (e.g. family members; males with breast cancer; or people with cancer in other sites, for example, prostate, lung) were included if data on the outcomes for women with breast cancer could be distinctly extracted. Otherwise, studies including participants other than women with breast cancer were excluded. All clinical and non-clinical settings of care (for example, home care, community institutions) were included.

Personal goal-setting

Criteria were designed to distinguish between studies where goal-setting was an important focus of the study and where goals were defined by the participant, rather than being goals identified or suggested by others. We specified that new personal goals had to be set, or existing personal goals identified, by the participant during the study. Studies examining

personal goal-setting in any life domain (e.g. relationships, occupational, or health) were included. Studies that examined organizational or group goal interventions, participant preferences (where participants select or rank goals from a provided list), or life values (e.g. longer life, professional success) were excluded. Preference lists are often derived and developed from general populations and it is not known whether they can be adopted and applied to women with breast cancer. Studies where participants set or articulated personal goals independently or in collaboration with others (e.g. interventionists) were included. Studies where someone other than the participant provided parameters for goal-setting (e.g. specifying goals within a life domain, timeframe, or for cancer treatment) were included, as long as the participant was involved in setting the actual goals, and the parameters themselves were not pre-defined goals. For example, a study where participants were asked to set weight loss goals was excluded, as the parameter of "weight loss" is itself a goal. Studies where someone other than the participant set the goals, or set or recommended an overall goal, followed by participant involvement in setting smaller, intermediate goals towards the overall goal, (e.g. weight loss goals, or researchers setting a goal of eventually exercising three times per week but allowing participants to set weekly goals of exercise frequency) were excluded. Treatment goals are directly relevant to women with breast cancer: treatment represents a significant, important part of life that requires external support.

We included studies that examined personal goal-setting as part of an intervention, as an outcome, or as a major variable (including confounders or effect modifiers). For cross-sectional studies (qualitative and quantitative data collection), studies were included if personal goal-setting was identified as a major variable. To be a major variable, a justification or theoretical basis for how personal goal-setting was related to other study variables had to be presented in the article's introduction or methods section. For experimental, cohort, and case-control studies,

personal goal-setting had to be included as a study intervention, exposure variable, outcome variable, effect modifier, or confounding variable. For studies (quantitative or qualitative) where personal goal-setting was an outcome or confounding variable, the study was included if the article's introduction presented a justification or theoretical basis for how personal goal-setting is related to other study variables. We focused this review's eligibility criteria for interventions on those interventions where personal goal-setting could be a mechanism towards a desired outcome for the intervention.[36] For studies where personal goal-setting was included as a study intervention, personal goal-setting had to be the sole intervention or a major component of a multi-component intervention. To be a major component, a justification or theoretical basis for how goal-setting is expected to affect the outcome had to be presented in the article's introduction or methods section. Studies where goal-setting was not a major component of an intervention were excluded. In studies where the intervention involved setting new personal goals, the personal goals had to be articulated, either verbally or in writing, during the intervention. Studies that encouraged or provided training or support for personal goal-setting without setting personal goals in the study were excluded.

Types of outcomes

All reported outcomes were included in the review. Measures could be subjective and self-reported (e.g. sleep loss reported by the participant) or objective (e.g. sleep loss measured by sleep monitor).

Other

Only studies published in English were included. Studies in any other language were excluded. Only published, full-length articles were included. Commentaries, letters, books, review articles, theses, dissertations, case studies, and conference abstracts were excluded. There were no restrictions on date of study or length of follow-up time.

3.4.4 Data Extraction

We extracted key information from included articles in a standardized Microsoft Excel data extraction form designed *a priori*. Two reviewers (AC, IP) independently extracted data from all articles to minimize errors. We piloted the data extraction form with 10% of included studies to determine if the form's instructions enable the reviewers to extract the desired data. We identified areas of disagreement in extracted data and the form was then refined, re-piloted with one more study, and finalized. Full data extraction was then conducted by both reviewers for the remaining studies.

For multiple but different articles that described data from a single study, data from the study was collated by extracting data from each article separately and then combining the information from multiple data abstraction forms.

3.4.5 Data items

Data extracted using our standardized form included: participant information (e.g. reported age, time since diagnosis), study information (e.g. design, country), methodology, intervention/exposure details (if applicable), primary and secondary outcome measures, and all reported results. The Template for Intervention Description and Replication (TIDieR) checklist was used to guide extraction of data about interventions.[37] We extracted information on goal-setting processes in study interventions, including their justification. For interventions where participants set personal goals, intervention descriptions were extracted as described in the papers, then characterized by coding using the Goals and Planning category (cluster 1) of the Behavior Change Technique taxonomy version 1 (BCTTv1), a detailed classification scheme for categorizing behavior change techniques in interventions.[38] We further classified those studies by whether or not interventions contained elements in addition to goal-setting and goal development, which we defined as elements that were included in the BCTTv1's cluster 1. If we

could not identify an intervention component as "goal-setting (outcome)" or "goal-setting (behavior)" as defined by the BCTTv1, we coded it as "goal-setting (outcome)" as recommended by the BCTTv1.[38] We extracted information on intervention methods to support participants to successfully pursue their goals, and the validity of instruments used to identify and rate personal goals.

3.5 RESULTS

3.5.1 Study selection

The literature search generated 5,187 citations with 5,140 identified from the electronic database searches and 47 through other sources (clinicaltrials.gov, conference abstracts, relevant reviews). After removing duplicates, we screened the titles and abstracts of 3,779 records. Of these, 242 records were retained as potentially eligible. Six studies were missing information necessary for determining eligibility. We contacted the authors and no response was received from three authors, thus we excluded those three respective studies.[39-41] Nine articles were identified from screened conference abstracts and eligible articles. A total of 13 articles, representing 12 studies, met eligibility criteria.[17,42-51] The citation for Sullivan-Singh et al[49] relates to data from two separate methods combined into one article. We identified them as two separate studies and distinguish them as "Sullivan-Singh 1" and "Sullivan-Singh 2". Two more articles[52,53] were identified that described different analyses of two of the included studies. Data was extracted from each article and we used the main articles[45,46] (those describing the results related to the study's primary objectives) to describe the study characteristics; otherwise, citations refer to the specific article from which a piece of information was extracted. The numbers of studies assessed, included and excluded at each stage are presented in a PRISMA flow diagram, detailed in Figure 1. A list of excluded studies, with reasons for exclusion, is

presented in Appendix 2.

Objective #1: How many studies examined personal goal-setting among women with breast cancer and what were the characteristics of these studies?

3.5.2 Study characteristics

Study characteristics are presented in Table 2. There were twelve studies with a total of 657 enrolled participants. Four studies[42,43,45,47] were randomized controlled trials (RCT); five[44,46,48,50,51] were quasi-experimental trial designs; two (including Sullivan-Singh 2) were prospective cohort studies,[17,49] and one, Sullivan-Singh 1, was a cross-sectional study.[49] Eight, including Sullivan-Singh 2, were single-group;[17,44-46,48-51] three, including Sullivan-Singh 1, were two-group,[43,47,49] and one study had three groups.[42] Seven of the twelve studies[42-46,50,51] were pilot or feasibility studies. Sample sizes ranged from 18 to 174 participants across all studies. The majority of studies were conducted in the USA (n=8),[42,43,45-49] two were conducted in Canada,[50,51] and single studies were conducted in the UK[44] and in Australia.[17] All but one study[43] were published after 2009, and most (n=8) were published after 2012.[17,42,44,46,47,49,50]

Reported study objectives

Reporting of primary and secondary objectives and outcomes varied across studies. One study did not specify a study objective.[44] Another study presented their objective in the study abstract, but not in the article text.[47] Of the four studies with multiple objectives, one study distinguished between primary and secondary objectives,[50] one listed two primary outcomes,[45] and two studies did not distinguish between primary and secondary objectives.[42,46] We grouped the stated or primary objectives of the included studies into three categories (one study was grouped into two categories).[46] In five studies, the stated or primary objective was to evaluate the effectiveness, feasibility or acceptability of a program or intervention.[42,44,45,50,51] Four studies

aimed to evaluate the effect of a program or intervention on health outcomes.[43,46-48] Three studies examined possible associations between variables or evaluated the utility of a theory.[17,49]

Reporting of outcomes

One study specified both primary and secondary outcomes.[17] Ten studies presented multiple outcomes without specifying a primary outcome, or specified multiple primary outcomes.[42,43,45-51] Sullivan-Singh 1 was an exploratory study evaluating associations between variables within a theoretical framework, the Socioemotional Selectivity Theory.[49] Three of the twelve studies measured outcomes at one time point, including Sullivan-Singh 1,[44,49,51] and the remaining nine studies measured them at least twice. Harcourt et al did not directly specify study outcomes or when outcomes were measured in relation to other study procedures.[44] Follow up time points ranged from hours after baseline to six months.

3.5.3 Participant characteristics

Participant characteristics are summarized in Table 2. Sullivan-Singh 1[49] included a control group of participants without breast cancer (n=50) whose outcomes have been excluded from description and analysis in this review. All participants in the included studies were adult females. The mean age ranged from 50.5 to 58 years for the six studies (n=423) that reported this statistic.[17,42-44,46,47] There was variability in the reporting of and across study populations regarding breast cancer stage, time since diagnosis, status related to breast cancer treatment, and demographic characteristics. For example, seven studies reported statistics related to time since breast cancer or metastatic breast cancer diagnosis,[42-44,47-49] two studies did not collect such data,[45,46] and three studies did not report time since diagnosis and the authors did not respond to enquiries about the collection of this data.[17,50,51] The descriptive statistics used to report time since diagnosis (mean, standard deviation, median, range, and mode) varied across the seven

studies. Nápoles et al's inclusion criteria stipulated diagnosis within the past year with more specific proportions reported (e.g. "more than 80% were enrolled within six months of diagnosis") but precise statistics were not reported.[47]

Objective #2: What were the characteristics of the intervention used in each study, that is, what comprised the intervention, who delivered the intervention, and when, where, and how was the intervention delivered?

3.5.4 Intervention characteristics

Eight studies described the setting and development of goals as part of the interventions;[42-47,50,51] intervention characteristics are presented in Table 3 and TIDieR checklists for each study are presented in Appendix 3. Four of the eight studies included a control group that received usual or standard care[42,43,45,46] three of which offered the intervention to the control group after the study was concluded.[43,44,47] Nápoles et al adapted Graves' New Directions intervention.[47] Two studies evaluated an intervention called the Survivorship Consult.[50,51] Lyons et al adapted Hegel's Problem-Solving Treatment – Occupational Therapy intervention.[46] As recommended by TIDieR,[37] all eight studies provided the name of their interventions and a rationale, theory, or aim of the intervention's key elements. All eight described the intervention procedures and six described at least one type of physical material used in the intervention.[44-47,50,51] One study mentioned the materials used in the intervention without description,[43] and one study did not report any materials used, but authors provided a facilitator's manual during e-mail correspondence.[42] No study provided information on how to access the materials reported.

All of the studies provided some but not all of the TIDieR-recommended information on who provided the intervention (e.g. disciplinary background, training). All eight studies described how the intervention was delivered. The majority (n=6) had a face-to-face intervention and two studies delivered their intervention by phone.[44,46] Cheung et al had two arms receiving

their intervention; one received a face-to-face intervention and the other received the intervention online.[42] Only one study conducted a group intervention;[43] the remainder delivered their intervention individually or did not specify whether the intervention was delivered individually or in groups.[42,44] All eight studies described the number, length and frequency of sessions, whether face-to-face or remote. Three studies examined single-session interventions.[44,50,51] The remaining five consisted of five to eight weekly sessions.[42,43,45-47] Average session lengths ranged from 35 to 90 minutes.

Five of the eight studies indicated explicitly that their intervention was tailored to participants, and how.[43,45,46,50,51] Five studies described in some manner the fidelity of the actual intervention to the planned intervention.[42,44-47] Four of these studies described methods of assessment of fidelity, though none described strategies used to maintain or improve fidelity.[42,45-47] Two of the studies reported the extent to which the intervention was delivered as planned.[44,46]

Objective #3: What instrument was used in each intervention to elicit and evaluate the personal goals of women with breast cancer?

3.5.5 Studies with goal-setting interventions

Of the eight studies with a goal-setting intervention, goal-setting and further development of the goals were the sole or primary component of the intervention in three of those studies.[44-46] Six studies used author-developed instruments to elicit participants' personal goals.[42-47] It was unclear if the instrument used was author-developed in the remaining studies.[50,51] All but one study[51] reported parameters or instructions given for the goals set in the study. Parameters or instructions were related to goal content, timing or other goal characteristics such as achievability. One study focused on treatment goals;[44] other specific parameters are described in Table 4. We categorized relevant intervention elements using the BCTTv1's Goals and Planning category of behavior change techniques.[38] All eight studies included goal-setting of behavior or

outcome goals, as defined by the BCTTv1.[38,42-47,50,51] Five studies (in six articles) included at least one other goal or planning-related technique.[42-46,52] In four of the studies, participants received help from an interventionist to set their goals.[44,47,50,51] Beyond eliciting the goals themselves, one of the eight studies quantitatively assessed goal characteristics. This study authored by Harcourt et al asked the surgeon who would be performing breast cancer surgery on the participant to rate the probability of achieving each goal of each participant.[47]

3.5.6 Studies without goal-setting interventions

Four of the twelve studies were studies of correlates of personal goals and measured goals set as a predictor or outcome variable.[17,48,49] Of the four studies measuring goals as a predictor or outcome variable, one study (Sullivan-Singh 2) used goals that were set as a predictor variable,[45] and three studies reported on goals set as an outcome variable.[17,48,49] Two of the four studies[49] used a published instrument to elicit participants' personal goals (Emmons' Strivings List).[6] The other two studies[17,48] used author-developed instruments. All four studies provided parameters or instructions for listing personal goals. Three studies, including the two using Emmons' Strivings List, asked participants to articulate important goals currently being sought or pursued;[17,49] the other asked participants to specify their goals for the study's intervention.[48] Beyond eliciting the goals themselves, one of the four studies assessed goal characteristics, asking participants to rate the importance of each goal.[17]

Objective #4: What were the primary results of the studies that used validated instruments?

3.5.7 Primary results

None of the 12 studies used validated instruments to set goals. We summarized the main results related to goal-setting and development of those goals and results related to intervention

evaluations in the 12 studies in Appendix 4. The context and methods for personal goal-setting in all included studies is presented in Table 4.

3.6 DISCUSSION

3.6.1 Summary and implications of findings

We found a small number of published studies (12) that examined personal goal-setting by women with breast cancer. There was significant variability across the included studies in terms of study design, objectives, methods, outcomes and reporting. Two-thirds of the studies enrolled fewer than 50 participants.[42-46,48,50,51] While studies were conducted in four different countries, the populations studied were generally homogenous in terms of ethnicity and education levels; most included studies had participants that were well-educated, Caucasian women. One study, however, the largest in this review, was composed of Latina women with relatively low levels of education.[47] The content of personal goals may vary depending on sociodemographic factors,[19,22,23] and the homogeneity of studied populations limits the ability to generalize the findings of this review even among women with a history of breast cancer. More studies in different cultural and socioeconomic contexts would improve the generalizability of our findings.

Only one study, Sullivan-Singh 1, compared the personal goals of women with breast cancer to women without a diagnosis, and found that women with breast cancer have fewer goals, and goals with a more limited timeframe.[49] The inclusion criteria, measurement and reporting of participant characteristics, varied across the included studies. Of particular importance is the variation in reported cancer-related characteristics. For example, only half the studies, including Sullivan-Singh 1, reported the time since breast cancer diagnosis.[42-44,47-49] Five studies reported an average time, with means or mode ranging from 9 to 33 months, indicating

that most of the included studies focused on participants that had likely completed active treatment and were at a stage often considered as post-active treatment survivorship.[42-44,48,49] This is an important time to work with women living with experiences of breast cancer, but our findings show that women's personal goals shortly after a diagnosis of breast cancer have not been well-captured in the literature. We found only two studies whose populations were all or mostly women within one year of diagnosis.[47,48] One presented no goal-related results;[47] the other asked participants to set goals related solely to the study intervention (a therapeutic modality) rather than to also include the breadth of other personal goals characterizing their life.[48] Cancer, treatment and physical symptoms can hinder someone's individual resources necessary to pursue meaningful goals.[13,17] More research is needed to understand the content and changes in women's important goals following a recent breast cancer diagnosis.

Most studies in our review did not use existing validated instruments to elicit or set participant goals. We were therefore unable to fulfill one study objective to present the results of studies using validated instruments. Using standardized or validated instruments, such as Emmons' Strivings List or the Behavior Change Techniques Taxonomy, to elicit or set goals in research studies would provide consistency in the ways in which personal goals are identified and facilitate comparison across studies. The Personal Projects Analysis is one such standardized instrument that has been used (but not validated) with people with cancer and other populations to elicit people's existing goals and ratings of goal characteristics such as importance that can be used to compare goals of broadly different content.[13,54,55] Only one study examined a quantitative, participant-reported measure of goal characteristics.[44] Because goal-setting is idiosyncratic in nature, quantitative measures enable comparison across studies and contributes to building an evidence base. We recommend future studies include quantitative measures of personal goals set or elicited, such as the Personal Projects Analysis.[54,55]

Most of the included studies that involved interventions were pilot or feasibility studies. All of the goal-setting interventions were explicitly based on an existing theory or framework. Building on existing research and knowledge is a strength of these interventions. Pilot or feasibility studies usually focus on measures of intervention feasibility or effectiveness; more studies are needed where the primary outcomes are considered important to women with breast cancer, such as quality of life. We recommend future, larger studies that evaluate such outcomes. In addition, the extent of reporting of intervention components, particularly intervention content, varied widely; only one of the included studies reported all intervention components recommended by TIDieR.[37] Full reporting of interventions is critical for implementation of those interventions by practitioners in a clinical setting, for replication if warranted, and for further research.

3.6.2 Strengths and limitations

A strength of our review was the use of established and accepted systematic review methods to identify and analyze studies, including systematic literature searches, screening, and a formalized extraction process. Another strength in the conduct of this scoping review is that we were able to chart the available published literature, which included a small number of studies that varied widely in design and methods. We recommend that further studies, using published or validated instruments or taxonomies, be undertaken on goal-setting for women with breast cancer before a full systematic review is conducted.

We excluded studies of patient preferences and studies where the participant was not involved in setting their personal goals. Because many lists are developed for a general population, we decided to focus on participant-generated goals; consequently, we may have missed some studies with relevant information on goal-setting with women with breast cancer. Future studies should examine whether and which personal goals elicited in this population align

with existing goal preference lists derived from general populations, and which may be more specific to the (breast) cancer experience per se. Furthermore, instruments with pre-defined goals are easier to validate than instruments without such goals. This exclusion criteria may have had an impact on our finding that few studies used validated instruments. For practical reasons, we limited our review to English-language articles and may have missed relevant studies published in other languages.

The personal goals of women with breast cancer is an important topic of growing interest. Ours is the first known synthesis of studies assessing personal goal-setting by women with breast cancer. A systematic review on life goals among people with cancer was published in 2016;[14] that review's inclusion criteria, however, differed from ours in important ways. The 2016 review included studies that specifically explored the association between cancer and life goals, whereas our review included studies in which participants set goals but did not specify particular associations with other variables. We also excluded studies where participants did not set their own goals, whereas Hullmann et al did not specify this criterion. Our study population was more narrowly focused on women with breast cancer. Only one study appeared in both reviews.[17] Six studies included in our review were published since Hullmann et al's search in 2014.[42,44,46,47,49] A list of reasons for article exclusion in the Hullmann review was not publicly available, and we do not know the authors' reasons for excluding the other five studies that were included in our review. We believe that it is likely that the exclusions were made because those studies did not look specifically at the impact of cancer on life goals. Our review offers insight into the kinds of goals that women with breast cancer have, identifies ways that existing interventions have employed goal-setting with this specific population, and in some cases, looks at the impact of those interventions on women with breast cancer.

3.7 CONCLUSION

For breast cancer care providers interested in patient-centred care and shared decision-making, personal goal-setting offers a technique for understanding the motivations and desired targets of women with breast cancer. Personal goals are important articulations of individual purpose, aspirations and hopes in daily life. To our knowledge, this is the first scoping review of personal goal-setting among women with breast cancer. Our review provides potential avenues for future research and consideration for developers of patient-centred care interventions for women with cancer. Our findings indicate that there are very few studies on personal goal-setting in this population and identifies several important gaps in the evidence base that can be considered for future studies. For example, we recommend more personal goal-setting studies with women recently diagnosed with breast cancer. The body of research on personal goal-setting among women with breast cancer is relatively recent. We recommend more research to better understand the personal goals of women following a breast cancer diagnosis and the factors that can help or hinder that pursuit. Such work would help to identify the pathways and mechanisms by which breast cancer care interventions can support women's goal-setting. These recommendations are important to the future development and study of interventions aimed at or involving goal-setting among women with breast cancer and that can be replicated, ultimately helping women to set and pursue goals that are meaningful to them.

3.8 FIGURES AND TABLES

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Figure 1. PRISMA flow document

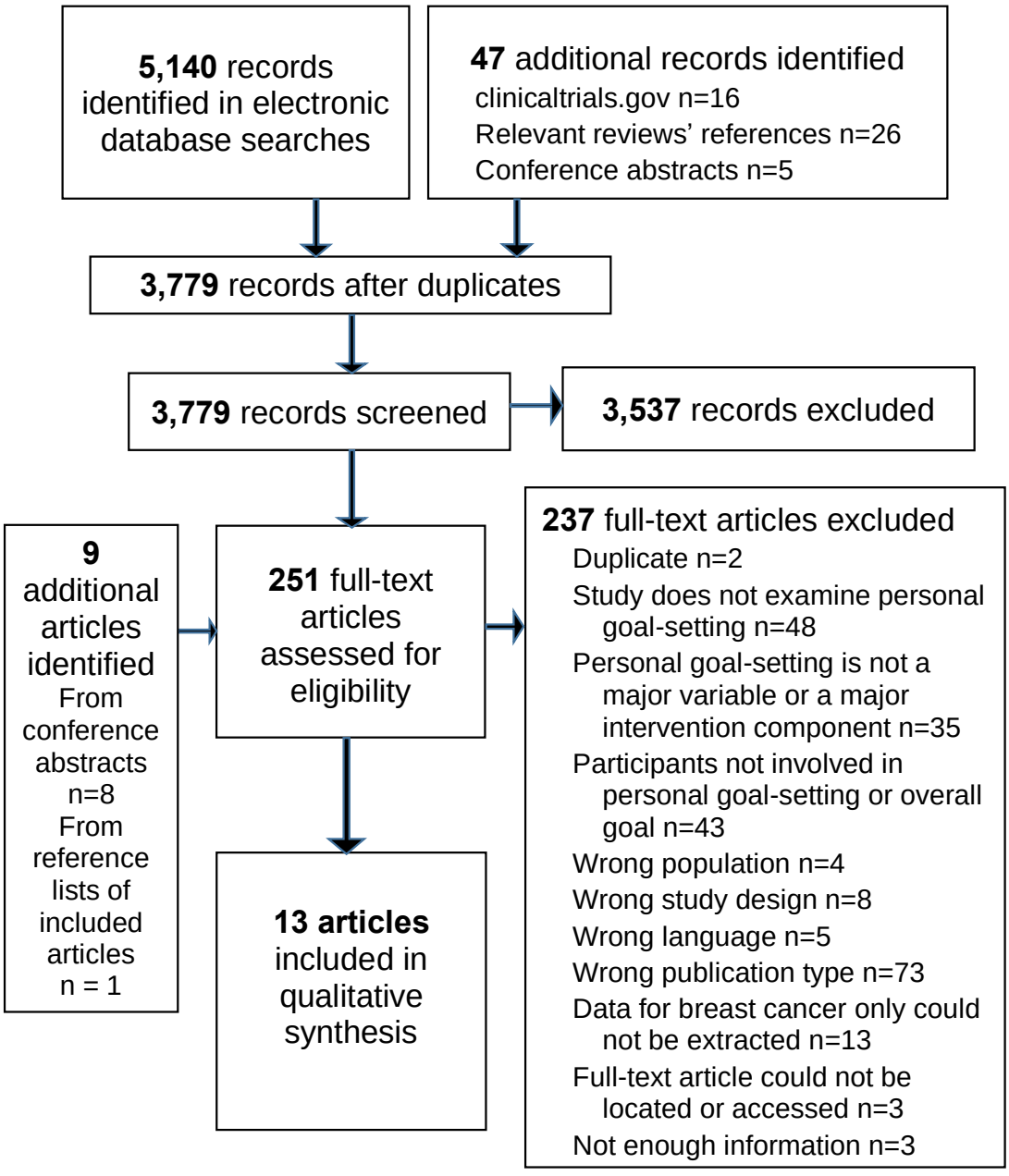

Table 1. Eligibility criteria

	Inclusion	Exclusion
Study design	Primary studies of any design excluding case studies	Systematic reviews and clinical guidelines
Participants	Females with a diagnosis of breast cancer	Studies including participants other than females with breast cancer and where outcome data for females with breast cancer cannot be extracted
Personal goal-setting as a study variable	Examines personal goal-setting in any life domain	Examines organizational/ group goals, participant preferences or life values
	The participant is involved in setting goals	The participant is not involved in setting goals or an overall goal is set or recommended by someone other than the participant
	Personal goal-setting is the sole or a major component of an intervention, or as an exposure, outcome variable or other major variable	Personal goal-setting is not a major or sole component of an intervention, exposure, outcome variable or other major variable
Personal goal-setting in interventions	If new personal goals set in the intervention, they were articulated verbally or in writing	Personal goals were not articulated verbally or in writing
		Training or support for goal-setting without goal-setting
Outcomes	All outcomes	n/a
Language	English	Anything other than English
Publication status	Published, full-length articles	Commentaries, letters, books, review articles, conference abstracts, theses or dissertations
Other	All study dates, length of follow-up, setting	n/a

Table 2. Study and participant characteristics

Authors & year	Country	N	Pilot or feasibility study	Age at baseline [years, M(SD)]	Breast cancer stage* [n (%)]	Treatment status*† [n (%)]	Time since diagnosis* [M(SD) or n (%)]	Primary objective
Randomized controlled trials								
Cheung et al 2016[42]	USA	39	Yes	53.35 (11.22) Range: 30 - 73	Inclusion criteria: Stage IV	Currently receiving treatment: 64%	M = 2.58 (3.12) years Range = 1 month - 12 years) since metastatic diagnosis	To examine the feasibility, acceptability, and preliminary efficacy of a positive affect skill intervention for women with breast cancer
Graves et al 2003[43]	USA	32	Yes	55.66 (10.75) Range: 35 – 81	0: 8 (25) I: 10 (31.3) II: 10 (31.3) III: 4 (12.5)	Had chemotherapy, radiation, lumpectomy or mastectomy: ≥23 (71.9)	M = 2.5 years since diagnosis 0–6 months: 2 (6.25%) 6-12 months: 11 (34.38%) ≥ 12 months: 19 (59.42%)	To enhance quality of life through a Social Cognitive Theory-based pilot intervention
Hegel et al 2011[44] / Lyons et al 2012[53]	USA	31	Yes	52.6 (9.4)	Inclusion criteria: Stage I, II, or III	Inclusion criteria: Currently in treatment (beginning 2nd cycle of chemotherapy)	Not collected $	To evaluate (1) recruitment and retention feasibility and (2) the acceptability of the Problem-solving and Occupational Therapy intervention[45] To summarize (1) the types of challenges that participants chose to focus on during the intervention, (2) the types of goals they set to respond to those challenges, and (3) the number and breadth of adaptive strategies they identified[53]
Napoles et al 2015[47]	USA	151	No	50.5 (10.9)	0: 40 (26) I: 23 (15) II: 57 (38) III: 31 (21)	Not reported	Inclusion criteria: ≤ 12 months since diagnosis ≤ 6 months since diagnosis: >80% ≤3 months since diagnosis: 47%	To assess the effect of the Nuevo Amanecer intervention on the quality of life of Latinas diagnosed with breast cancer
Quasi-experimental trials								
Harcourt et al 2015[44]	U.K.	18	Yes	51.06 (10.40) Range: 33–77	Invasive: 14 (78) DCIS: 3 (17)	Chemotherapy or radiotherapy: 12 (67)	M = 33.41 months (46.41) Range = 1- 192 months $	Not stated. Article reports on the acceptability of PEGASUS intervention
Lyons et al 2015a and b[46,52]	USA	32	Yes	Stage 1: 52 (6) Stage 2: 46 (7)	<u>Stage 1:</u> I: 6 (40) II: 7 (47) III: 2 (13) <u>Stage 2:</u> I: 3 (19) II: 8 (50) III: 5 (31)	Inclusion criteria: chemotherapy completed within past 6 months	<6 months since completion of adjuvant treatment. $	To develop the treatment manual and assess the acceptability, feasibility, and potential efficacy of the intervention
Searls & Fawcett 2011[48]	USA	31	No	58 (no SD) Range = 31 - 75	Not reported	Receiving adjuvant treatment: Yes - 19 (66), No - 10 (34) Dropouts: n=2	Mode: 9 months, range 1 – 31 months since diagnosis	To evaluate the effectiveness of Jin Shin Jyutsu energy medicine on women in or who have completed breast cancer treatment

Authors & year	Country	N	Pilot or feasibility study	Age at baseline [years, M(SD)]	Breast cancer stage* [n (%)]	Treatment status*† [n (%)]	Time since diagnosis* [M(SD) or n (%)]	Primary objective
Wiljer et al 2013[50]	Canada	35	Yes	M(SD) not reported Range: 42.3% between 55 – 64	Not reported	Not reported	Not reported	To evaluate the Survivorship Consult intervention
Wiljer et al 2010[51]	Canada	40	Yes	M(SD) not reported Range: 75% between 41 - 60	II: 16 (44.4) III: 14 (38.8) Not reported: 10 (16.8)	Currently receiving treatment at the hospital: 22 (55)	Not reported	To determine the impact of the reflective interview on self-efficacy and the perceived likelihood that it initiates behavior change (usefulness to the patient).
Prospective cohort studies								
Stefanic et al 2014[17]	Australia	52	No	58 (11.70) Range 33 - 76	I, II, or IIIA: 35 (81.4) DCIS: 7 (16.3) Unknown: 1 (2.3)	Not receiving adjuvant therapy: n=33	Not reported	To improve understanding of the relationship between breast cancer physical symptom burden and cancer-related goal interference
Sullivan-Singh et al 2015-1[49]	USA	174	No	EG: 57.46 (10.74)	Inclusion criteria for EG: Stage IV	Not reported	EG: 32.86 (29.86) months since diagnosis of metastatic cancer	To use socioemotional selectivity theory to evaluate cognitive biases and life goals
Prospective cohort study and cross-sectional study								
Sullivan-Singh et al 2015-2[49]	USA	#	No	Not reported	Inclusion criteria: Stage IV	Not reported	Mean not reported Range: 1 – 126 months	To investigate the association between time perspective goals and psychological adjustment in women with metastatic breast cancer

DCIS = ductal carcinoma in situ, EG = exposed group, M (SD) = mean (standard deviation), N = number of participants at enrollment, n= number of participants at baseline.
*At baseline
†Treatment status: treatment is defined as any primary or adjuvant therapy except hormone therapy.
ˢData received via email from authors
Although the two studies by Sullivan-Singh et al are treated separately in this review, the Study 2 population is a subset of the Study 1 population (exposed group members who provided data on life goals)

Table 3. Intervention characteristics

Authors & year	Comparisons	Name	Aim	Processes	Delivery mode & setting	Timing, length & frequency	Who delivered	Behaviour Change Techniques †	Relevant intervention-related results
Cheung et al 2016[42]	OL intervention vs IP intervention vs attention-matched control	LILAC (Lessons in Linking Affect and Coping)	To increase participants' positive affect	(1) Teaching of 8 skills designed to increase the frequency of pts' positive emotions; (2) Daily practice of each skill until the next session. Goals set and pts instructed to identify ways to apply personal 'strengths' in goal pursuit $	IP: in person at University of California, San Francisco; OL: online. Group sizes not reported	5 weekly, one-hour sessions	IP: a trained facilitator; OL: no person.	Goal setting (outcome) (1.3); action planning (1.4)	No differences found between IP and OL groups on any feasibility or acceptability measure. No between-group differences (combined IP and OL LILAC group vs control group) found in changes over 1 month in measures of psychological well-being or positive coping
Graves et al 2003[43]	Intervention vs standard care control group	New Directions	To improve self-efficacy, outcome expectations, and self-regulatory skills	(1) Teaching of skills for relaxation, cognitive restructuring & assertive communication, dealing with stress, daily activities, changing images & future expectations of life with cancer; (2) Practice of learned skills & provision of feedback on that practice; (3) Weekly goal-setting related to the week's topic, identification of sub-goals towards the larger goal $	Setting not reported Small groups	8 weekly, 90-minute sessions	A doctoral candidate in clinical psychology (author) & a trained clinical psychology intern	Goal setting (outcome) (1.3); action planning (1.4)	While specifics were not provided, it was reported that women in the intervention group showed statistically significantly greater improvement or statistically significantly less decline than women in the control group for 17 of 23 measures of quality of life, mood, self-efficacy, outcome expectations and self-regulation.
Harcourt et al 2015[44]	None. Single-arm	PEGASUS (Patients' Expectations and Goals: Assisting Shared Understanding of Surgery)	To identify surgery expectations, set patient-centred goals, and facilitate related discussion	(1) With psychologist's help, pt's goals for surgery and her indicators of a successful outcome identified and written on PEGASUS sheet. Pt rating of each goal on its importance; (2) PEGASUS sheet is reviewed by the surgeon (3) Surgeon and pt discuss how realistic goals are, then final decisions about surgery are made.	Face to face at a large public hospital that offers breast reconstructive procedures Group size not reported	Once-off, after specific surgical options have been discussed	A psychologist facilitated goal-setting. A surgeon rated likelihood of goal success & discussed expectations with pts	Goal setting (outcome) (1.3); review outcome goal (1.7)	3 qualitative themes related to the acceptability of PEGASUS were identified: (1) PEGASUS improved communication between pt & clinician in breast reconstruction decision-making process; (2) Health professionals interviewed did not expect some of the expectations that pts identified during PEGASUS; and (3) The PEGASUS sheet was used according to protocol in 9 (75%) consultations.
Hegel et al 2011[45]	Intervention vs usual care control group	PST-OT (Problem-solving Treatment-Occupational Therapy)	To help participants address functional challenges in survivorship	(1) Identification of at least moderately important & at least moderately difficult activities & participation restrictions; (2) Goal-setting; (3) Brainstorming & evaluation of possible solutions; (4) Selection of a solution; (5) Development & implementation of an action plan; (6) In sessions 2 – 6, action plan review and adjustment as needed; (7) Encouragement of engagement in healthy activities	Telephone Individual	6 weekly sessions	An occupational therapist not involved in participants' clinical care	Goal setting (behavior) (1.1); action planning (1.4); review behavior goal (1.5)	92% of the intervention group rated the intervention as helpful or very helpful for participating in difficult but important activities. Mean scores for pt efforts to implement their action plan, degree of completion of the action plan, and degree of reduction of participation restrictions were 8.0, 8.8 and 6.8, respectively (interventionist rated, scale of 0=none to 10=completely).
Lyons et al 2015a and b[46,52]	None. Single-arm	BA/PS (Behavioral Activation/ Problem-Solving)	To reduce barriers to participating in valued activities	(1) Identification of challenging activities & reasons why activity was challenging; (2) Goal-setting; (3) If problem-solving was used: brainstorming of possible solutions to achieving goals, assessment of each solution; (4) Selection of a solution and construction of a detailed action plan to implement the solution; (5) Assessment of	Telephone Group size not reported	9 sessions: 6 weekly followed by 3 monthly	Stage 1: An occupational therapist Stage 2: Not specified	Goal setting (behavior) (1.1); action planning (1.4); review behavior goal (1.5); discrepancy	Dropout rate was 40% in Stage 1 and 41.2% in Stage 2. Across the whole study, all 19 completers rated the intervention as mostly or very helpful. Most (n=18) were mostly or very satisfied with the intervention and 18 thought the session topics were mostly or very relevant. Pre-post intervention ratings of quality of life and 4 of

Authors & year	Comparisons	Name	Aim	Processes	Delivery mode & setting	Timing, length & frequency	Who delivered	Behaviour Change Techniques †	Relevant intervention-related results
				how well the goal was met and the activity was performed				between current behavior and goal (1.6)	14 domains of coping style improved (after no change during a run-in period). Improvements also seen in depression and anxiety ratings but increases began during the run-in period.
Napoles et al 2015[47]	Intervention vs usual-care control group	Nuevo Amanecer (New Dawn)	To improve coping with cancer through improved self-efficacy, coping skills and social support	Session topics: managing the initial impact of cancer, finding cancer information, getting support, identifying helpful and unhelpful thoughts, managing thoughts and mood, stress management techniques, managing activities that affect mood, and goal setting	Face to face at participants' homes Individual	8 weekly sessions	Compañeras: Latina, Spanish speaker, ≥3 yrs since breast cancer diagnosis with no recurrence, completed active treatment	Goal setting (outcome) (1.3)	There was a significant intervention by time effect on overall quality of life (QOL) over 6 months (p=0.03), but not over the first 3 months. There was a significant effect at 3 months for 1 of 4 measures of distress (somatization) and at 6 months for 2 measures (somatization and depression).
Wiljer et al 2013[50]	None. Single-arm	SC (Survivorship Consult)	To empower participants and encourage participation in managing survivorship care	(1) Review of participants' breast cancer diagnosis & treatment, available support systems, and survivorship needs & goals; (2) Development of an action plan addressing participants' individual physical, social, emotional & spiritual needs; (3) Provision of appropriate support, education and information access throughout treatment	Face to face at the BCSP at Princess Margaret Cancer Centre (PMCC) Group size not reported	One 1-hour long session during 1st visit to the BCSP	A supportive care clinician (e.g. social worker, nurse) from the PMCC's Survivorship Clinic	Goal-setting (outcome) (1.3)	Key qualitative themes related to pt experience and impact of SC were identified: (1) Pts felt supported by the SC's collaborative dialogue; (2) Individual goal-setting motivated pts to pursue the clinician-recommended actions; (3) SC helped pts better understand breast cancer and treatment options; (4) SC helped with needs identification; (5) SC helped pts gain confidence to manage their care; and (6) There was no consensus on how to schedule the SC.
Wiljer et al 2010[51]	None. Single-arm	SC (Survivorship Consult)	To empower participants and encourage participation in managing survivorship care	(1) Collaborative creation of an action plan addressing pt's individual goals, information, education, and support needs; (2) Provision of information on relevant clinical and community services, programs and resources	Face to face at the BCSP at the PMCC Group size not reported	One 1-hour long session during 1st visit to the BCSP	Social worker or psychologist	Goal-setting (outcome) (1.3)	There was a significant increase in self-efficacy pre-post intervention measured by the Cancer Behavior Inventory (p=0.03) but not by the Stanford Self-Efficacy Scale. Pts found many informational aspects of the SC "very useful" (e.g. information on diagnosis and treatment – 75%, care plan recommendations – 80%). On perceived likelihood of initiating behaviour change, 80% reported that it was "very likely" that they would seek more diagnosis and treatment information and 61% believed they would implement their action plans.

OL = online; IP = in-person; BCSP = Breast Cancer Survivorship Program; pt = participant

$ Data received via email/additional materials from authors

† From Cluster 1 (Goals and Planning) of the Behaviour Change Techniques taxonomy[34]

Table 4. Context and methods of personal goal-setting in included studies

Authors & year	Role of goal-setting	Goal parameters or instructions for goal content	Who was involved in goal-setting	Instrument used to set goals	Other strategies/techniques included alongside goal setting (interventions only)	Assessment of goal characteristics (quantitative)	Primary goal-related results
Randomized controlled trials							
Cheung et al 2016[42]	Intervention component	"Attainable" goals for the week	Pt only	In-person condition: Author-developed, hard-copy workbook. Online condition: Author-developed website *Not validated*	Pts asked to identify a top strength and how to apply it to making progress on each goal$	No	None reported
Graves et al 2003[43]	Intervention component, outcome (questionnaire item within composite "outcome expectations" construct)	Goals for the program & unspecified goals; measurable with specific outcomes & reasonable timeline $	Pt only	Author-developed workbook *Not validated*	Pt asked to write, for each goal, "Plan on how to get there" and "first steps to take" $	No	The intervention group had significantly higher pre-post intervention change scores for outcome expectations related to goal-setting (*d*=1.58) than the control group, a greater difference in effect than any other outcome variable measured.
Hegel et al 2011[45] / Lyons et al 2012[53]	Intervention component, outcome	Goals for challenging but important activities; behavioral, observable, achievable	Pt only	Author-developed workbook *Not validated*	Intervention includes development of an action plan (AP) with strategies for goal attainment. Each week, pts asked to describe the results of the previous week's AP	No	Most common activities targeted by goals set: exercise (n=11 pts); daily functional activities (n=7); paid work (n=5), nutrition (n=5), or sleep (n=5). Goal types set: Adapt an activity (eg to make it easier, less stressful, etc) (n=12 pts), find a new activity (n=11), plan an activity (n=9), and gather information on how to do an activity (n=4).
Napoles et al 2015[47]	Intervention component	Goals related to "practice of stress management skills"; "realistic, specific, measurable"$	Pts with help from peer educators	Author-developed structured form *Not validated*	Pts were instructed to include a reward upon achievement of the goal; include family & friends as sources of support for achieving the goals	No	None reported
Quasi-experimental trials							
Harcourt et al 2015[44]	Intervention component, outcome	Goals for surgery	Pts, with review & rating of likelihood of success by a surgeon	Author-developed PEGASUS sheet *Not validated*	Each goal is rated by the surgeon on likelihood of success and discussed with the pt	Surgeon rates probability of achieving goals	Pts set 79 goals (M=4.38, range 2-6 per pt); 78.4% of goals rated 9 or 10 out of 10 on importance (range 5-10). Most common goal content themes: To look 'normal' (n=15); to be able to wear 'normal' clothes (n=13); to feel 'normal' (n=11); to avoid using a prosthesis (n=11)
Lyons et al 2015[46,52]	Intervention component, outcome	Goals related to "activities they wanted to do but found challenging"; measurable & achievable within 7 days; encouraged to	Pt only	Author-developed worksheets *Not validated*	Pts guided to develop action plan for goal attainment; use a workbook to monitor goal progress	No	There were 141 goals set (median 7, range 5 - 15 per pt) and 69% of them were achieved. Eight participants met ≥80% of their set goals, 7 met 50-79%, & 2 met ≤40%. The most common goals set were exercise (n=12), work (n=7), daily functional activities (n=7), social (n=7), stress management or relaxation (n=6). Goal types set: 66 goals

		set "goals for activities that supported their health…and other aspects of functioning"					(47%) to "do more" or adding a new activity (n=66 goals, 47%), improve an existing activity (n=75, 53%)
Searls & Fawcett 2011[48]	Outcome	Goals for Jin Shin Jyutsu treatment sessions	Pt only	Author-developed list *Not validated*	n/a	No	27 (93%) participants reported their goals for the intervention were achieved. Authors presented 4 themes related to goal content: improved physical well-being, improved emotional well-being, improved balance in life, and the desire to live a fuller life
Wiljer et al 2013[50]	Outcome	Survivorship goals	Collaborative process between pt & interventionist	Online forms through eCancer platform † *Not validated*	To address individual needs, goals & priorities, the pt and interventionist collaborate on developing an individualized action plan	No	Qualitatively, participants reported that goal-setting in the intervention helped to motivate them to pursue the strategies suggested by the clinician interventionist
Wiljer et al 2010[51]	Intervention component, outcome	Not reported	Collaborative process between pt & interventionist	Online forms through eCancer platform † *Not validated*	Pts receive a treatment summary and care plan summarizing goals and actions to achieve those goals	No	None reported
Prospective cohort studies							
Stefanic et al 2014[17]	Outcome	"Important" goals that they were currently pursuing	Pt only	Not reported	n/a	Pt rated importance & perceived current cancer-related interference with goals	The number of goals identified differed significantly across time (p =.041). Cancer-related goal interference significantly changed over time (p =.007). Having higher physical burden was significantly associated with higher cancer-related goal interference at ~2, 4 and 6 months post-surgery, but not at 1 month after
Sullivan-Singh et al 2015-2[49]	Predictor variable	"Goals, or 'strivings,' that they were currently seeking in their everyday behavior"	Pt only	Emmons' striving list *Not validated*	n/a	No	'Composite expansive' (more distant) TPG predicted a decrease in perceived cancer-related benefits over 3 months; there was no association between 'composite limited' (more proximate) TPG and cancer-related benefits. No association found between TPG and cancer-specific distress over 3 months, but there was a significant interaction between marital status and limited TPG: For unmarried women, limited TPG predicted lower cancer-specific distress over 3 months (p=0.001); no association for married women
Prospective cohort study and cross-sectional study							
Sullivan-Singh et al 2015-1[49]	Outcome	"Goals, or 'strivings,' that they were currently seeking in their everyday behavior"	Pt only	Emmons' striving list *Not validated*	n/a	No	The 'exposed' group set 113 goals. They had significantly fewer goals M(SD) = 6.52(2.78) than women without metastatic BC 8.92(4.58) and stronger preference for limited TPG compared to expansive TPG than women without metastatic BC: (p = .001)

BC = breast cancer; M = mean; SD = standard deviation; Pt = participant, TPG = time perspective goals

$ Data received via email/additional materials from authors

† Unclear if the form was author-developed or if the eCancer platform is available to others

3.9 REFERENCES FOR CHAPTER 3

1. Austin JT, Vancouver JB. Goal constructs in psychology: Structure, process, and content. Psychol Bull. 1996;120:338–75.

2. Elliot A, Thrash T. Achievement goals and the hierarchical model of achievement motivation. Educ Psychol Rev. 2001;13:139–56.

3. Ryan RM, Deci EL. Self-determination theory and the facilitation of intrinsic motivation, social development, and well-being. Am Psychol. 2000;55:68–78.

4. Locke EA, Shaw KN, Saari LM, Latham GP. Goal setting and task performance: 1969-1980. Psychol Bull. 1981;90:125–52.

5. Scobbie L, Dixon D, Wyke S. Goal setting and action planning in the rehabilitation setting: development of a theoretically informed practice framework. Clin Rehabil. 2011;25:468–82.

6. Emmons RA. Personal strivings: An approach to personality and subjective well-being. J Pers Soc Psychol. 1986;51:1058–68.

7. Brunstein JC. Personal Goals and Subjective Well-Being: A Longitudinal Study. J Pers Soc Psychol. 1993;65(5):1061-1070.

8. Carver CS, Scheier MF. Principles of self-regulation: Action and emotion. In: Higgins ET, Sorrentino RM, eds. Handbook of motivation and cognition: Foundations of social behavior. New York, NY: The Guilford Press; 1990. p. 3–52.

9. Freund AM. Differentiating and integrating levels of goal representation: a life span perspective. In: Little BR, Philips SD, Salmela-Aro K, editors. Personal project pursuit: goals, action, and human flourishing. Mahwah, N.J.: Lawrence Erlbaum Associations; 2007. p. 247–70.

10. Klug HJP, Maier GW. Linking goal progress and subjective well-being: a meta-analysis. J Happiness Stud. 2015;16:37–65.

11. Sheldon KM, Kasser T. Goals, Congruence, and Positive Well-Being: New Empirical Support for Humanistic Theories. Nal Humanist Psychol. 2001;41:30–50.

12. Sheldon KM, Kasser T. Pursuing Personal Goals: Skills Enable Progress, but Not all Progress is Beneficial. Pers Soc Psychol Bull. 1998;24:1319–31.

13. Peterman A, Lecci L. Personal projects in health and illness. In: Little BR, Philips SD, Salmela-Aro K, editors. Personal project pursuit: goals, action, and human flourishing. Mahwah, N.J.: Lawrence Erlbaum Associations; 2007. p. 329–53.

14. Hullmann SE, Robb SL, Rand KL. Life goals in patients with cancer: a systematic review of the literature: Life goals in patients with cancer. Psychooncology. 2016;25:387–99.

15. Sulkers E, Janse M, Brinksma A, Roodbol PF, Kamps WA, Tissing WJE, et al. A longitudinal case–control study on goals in adolescents with cancer. Psychol Health. 2015;30:1075–87.

16. Gagliese L, Jovellanos M, Zimmermann C, Shobbrook C, Warr D, Rodin G. Age-Related Patterns in Adaptation to Cancer Pain: A Mixed-Method Study. Pain Med. 2009;10:1050–61.

17. Stefanic N, Caputi P, Iverson DC. Investigating physical symptom burden and personal goal interference in early-stage breast cancer patients. Support Care Cancer. 2014;22:713–20.

18. Janse M, Sprangers MAG, Ranchor AV, Fleer J. Long-term effects of goal disturbance and adjustment on well-being in cancer patients. Qual Life Res. 2016;25:1017–27.

19. Roberts BW, Robins RW. Broad Dispositions, Broad Aspirations: The Intersection of Personality Traits and Major Life Goals. Pers Soc Psychol Bull. 2000;26:1284–96.

20. Canadian Cancer Society's Committee on Cancer Statistics. Canadian Cancer Statistics 2016. Toronto, ON: Canadian Cancer Society; 2016.

21. National Cancer Institute - Surveillance, Epidemiology, and End Results Program. SEER*Explorer: An interactive website for SEER cancer statistics. https://seer.cancer.gov/explorer/. Accessed 20 Aug 2018.

22. Nurmi J-E, Pulliainen H, Salmela-Aro K. Age differences in adults' control beliefs related to life goals and concerns. Psychol Aging. 1992;7:194–6.

23. Nurmi J-E. Age Differences in Adult Life Goals, Concerns, and Their Temporal Extension: A Life Course Approach to Future-oriented Motivation. Int J Behav Dev. 1992;15:487–508.

24. Lam WWT, Yeo W, Suen J, Ho WM, Tsang J, Soong I, et al. Goal adjustment influence on psychological well-being following advanced breast cancer diagnosis: Goal adjustment and psychological well-being. Psychooncology. 2016;25:58–65.

25. Low CA, Stanton AL. Activity disruption and depressive symptoms in women living with metastatic breast cancer. Health Psychol. 2015;34:89–92.

26. Mens MG, Scheier MF. The Benefits of Goal Adjustment Capacities for Well-Being Among Women With Breast Cancer: Potential Mechanisms of Action: Goal Adjustment, Well-Being, and Breast Cancer. J Pers. 2016;84:777–88.

27. Ng AV, Cybulski AN, Engel AA, Papanek PE, Sheffer MA, Waltke LJ, et al. Triathlon training for women breast cancer survivors: feasibility and initial efficacy. Support Care Cancer. 2016. doi:10.1007/s00520-016-3531-5.

28. Otto AK, Szczesny EC, Soriano EC, Laurenceau J-P, Siegel SD. Effects of a randomized gratitude intervention on death-related fear of recurrence in breast cancer survivors. Health Psychol. 2016;35:1320–8.

29. Stefanic N, Iverson DC, Caputi P, Lane L. Examining the influence of personal goal interference and attainability on psychological distress in non-metastatic breast cancer patients. Eur J Cancer Care (Engl). 2016. doi:10.1111/ecc.12494.

30. Xia H-Z, Gao L, Yue H, Shi B-X. Exploring Meaning in the Life of Chinese Breast Cancer Survivors. Cancer Nurs. 2016;:1–7.

31. Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group. Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med. 2009;6:e1000097.

32. Chow A, Presseau J, Perelman I, Sikora L, Fergusson D. Personal goal-setting among women living with breast cancer: protocol for a scoping review. Syst Rev. 2018;7:132.

33. Levack WM, Weatherall M, Hay-Smith EJC, Dean SG, McPherson K, Siegert RJ. Goal setting and strategies to enhance goal pursuit for adults with acquired disability participating in rehabilitation. In: The Cochrane Collaboration, editor. Cochrane Database of Systematic Reviews. Chichester, UK: John Wiley & Sons, Ltd; 2015.

34. Clarivate Analytics. EndNote X7. https://clarivate.com/products/endnote/.

35. Veritas Health Innovation. Covidence. Melbourne, Australia. www.covidence.org.

36. Michie S, Johnston M, Carey R. Behavior Change Techniques. In: Gellman M, ed. Encyclopedia of Behavioral Medicine. New York, NY: Springer; 2019.

37. Hoffmann TC, Glasziou PP, Boutron I, Milne R, Perera R, Moher D, et al. Better reporting of interventions: template for intervention description and replication (TIDieR) checklist and guide. BMJ. 2014;348 mar07 3:g1687–g1687.

38. Michie S, Richardson M, Johnston M, Abraham C, Francis J, Hardeman W, et al. The Behavior Change Technique Taxonomy (v1) of 93 Hierarchically Clustered Techniques: Building an International Consensus for the Reporting of Behavior Change Interventions. Ann Behav Med. 2013;46:81–95.

39. Hatchett A, Hallam JS, Ford MA. Evaluation of a social cognitive theory-based email intervention designed to influence the physical activity of survivors of breast cancer: SCT, physical activity and email. Psychooncology. 2013;22:829–36.

40. Kvale EA, Huang CS, Meneses KM, Demark-Wahnefried W, Bae S, Azuero CB, et al. Patient-centered support in the survivorship care transition: Outcomes from the Patient-Owned Survivorship Care Plan Intervention. 2016;122:3232–42.

41. Anderson BO, Shyyan R, Eniu A, Smith RA, Yip C, Bese NS, et al. Breast cancer in limited-resource countries: an overview of the Breast Health Global Initiative 2005 guidelines. Breast J. 2006;12:S3-15.

42. Cheung EO, Cohn MA, Dunn LB, Melisko ME, Morgan S, Penedo FJ, et al. A randomized pilot trial of a positive affect skill intervention (lessons in linking affect and coping) for

women with metastatic breast cancer: A Positive Affect Intervention for Women with Metastatic Breast Cancer. Psychooncology. 2016. doi:10.1002/pon.4312.

43. Graves KD, Carter CL, Anderson ES, Winett RA. Quality of life pilot intervention for breast cancer patients: use of social cognitive theory. Palliat Support Care. 2003;1:121–34.

44. Harcourt D, Griffiths C, Baker E, Hansen E, White P, Clarke A. The acceptability of PEGASUS: an intervention to facilitate shared decision-making with women contemplating breast reconstruction. Psychol Health Med. 2016;21:248–53.

45. Hegel MT, Lyons KD, Hull JG, Kaufman P, Urquhart L, Li Z, et al. Feasibility study of a randomized controlled trial of a telephone-delivered problem-solving-occupational therapy intervention to reduce participation restrictions in rural breast cancer survivors undergoing chemotherapy. Psychooncology. 2011;20:1092–101.

46. Lyons KD, Hull JG, Kaufman PA, Li Z, Seville JL, Ahles TA, et al. Development and Initial Evaluation of a Telephone-Delivered, Behavioral Activation, and Problem-Solving Treatment Program to Address Functional Goals of Breast Cancer Survivors. J Psychosoc Oncol. 2015;33:199–218.

47. Nápoles AM, Ortíz C, Santoyo-Olsson J, Stewart AL, Gregorich S, Lee HE, et al. Nuevo Amanecer: results of a randomized controlled trial of a community-based, peer-delivered stress management intervention to improve quality of life in Latinas with breast cancer. 2015;105 Suppl 3:e55.

48. Searls K, Fawcett J. Effect of Jin Shin Jyutsu energy medicine treatments on women diagnosed with breast cancer. J Holist Nurs Off J Am Holist Nurses Assoc. 2011;29:270–8.

49. Sullivan-Singh SJ, Stanton AL, Low CA. Living with limited time: Socioemotional selectivity theory in the context of health adversity. J Pers Soc Psychol. 2015;108:900–16.

50. Wiljer D, Urowitz S, Jones J, Kornblum A, Secord S, Catton P. Exploring the use of the survivorship consult in providing survivorship care. Support Care Cancer. 2013;21:2117–24.

51. Wiljer D, Urowitz S, Frasca E, Nyhof-Young J, Secord S, Walton T, et al. The Role of a Clinician-Led Reflective Interview on Improving Self-Efficacy in Breast Cancer Survivors: A Pilot Study. J Cancer Educ. 2010;25:457–63.

52. Lyons KD, Svensborn IA, Kornblith AB, Hegel MT. A Content Analysis of Functional Recovery Strategies of Breast Cancer Survivors. OTJR Occup Particip Health. 2015;35:73–80.

53. Lyons KD, Erickson KS, Hegel MT. Problem-Solving Strategies of Women Undergoing Chemotherapy for Breast Cancer. Can J Occup Ther. 2012;79:33–40.

54. Little BR. Personal projects: a rationale and method for investigation. Environ Behav. 1983;15:273–309.

55. Little B, Gee T. The methodology of Personal Projects Analysis: four modules and a funnel. In: Little BR, Philips SD, Salmela-Aro K, editors. Personal project pursuit: goals, action, and human flourishing. Mahwah, N.J.: Lawrence Erlbaum Associations; 2007. p. 51–93.

56. Cohn MA, Pietrucha ME, Saslow LR, Hult JR, Moskowitz JT. An online positive affect skills intervention reduces depression in adults with type 2 diabetes. J Posit Psychol. 2014;9:523–34.

57. Nápoles AM, Santoyo-Olsson J, Ortiz C, Gregorich S, Lee HE, Duron Y, et al. Randomized controlled trial of Nuevo Amanecer: A peer-delivered stress management intervention for Spanish-speaking Latinas with breast cancer. Clin Trials J Soc Clin Trials. 2014;11:230–8.

Appendix 1 – Amendments to the Protocol

Amendments made to the protocol after original protocol finalized July 5, 2017

Date	Section	Original protocol	Revised protocol	Rationale
July 17, 2017	Methods: Eligibility criteria, Table 1	Personal goal-setting was discussed only as an element of study interventions or exposures.	We will include the following new information regarding eligibility of studies: **Inclusion of personal goal-setting** We will include studies which include personal goal-setting. We will identify how personal goals are elements of the study (as an intervention, key variable in data collection, outcome, etc) and report this information in the Results section. For cross-sectional studies (qualitative and quantitative data collection), studies will be included if personal goal-setting is identified as a major variable. To be a major variable, the article's introduction should present a justification or theoretical basis for how personal goal-setting is hypothesized to be related to other study variables. For experimental, prospective and retrospective cohort, and case-control studies, studies must include personal goal-setting as a study intervention, exposure variable, outcome variable, effect modifier, or confounding variable. We add a definition: we employ the general term "interventions" in the protocol to mean study interventions which may include programs, projects, or organizational interventions. We clarify that personal goal-setting may be the sole intervention or a major component of a multi-component intervention. The sentence "Studies where goal-setting is not a major component of the intervention will be excluded" will be changed to "Studies where the intervention has multiple components and goal-setting is not a major component will be excluded." We amend the protocol to add that, for studies where personal goal-setting is an outcome or confounding variable, a study will be included if the article's introduction presents a justification or theoretical basis for how personal goal-setting is hypothesized to be related to other study variables.	To address this scoping review's overall objective, particularly research question #1, it is important to include all studies where personal goal-setting is a variable.
July 17, 2017	Methods: eligibility criteria – types of interventions/ exposures, Table 1	Protocol outlined inclusion or exclusion depending on whether someone other than the participant provides parameters for goals, or sets or	We clarify the definition of "parameters" for goals. Parameters must not be goals, for example, asking participants to set health-related goals or social goals would be included. A study where participants are asked to set weight loss goals would be excluded, as weight loss is a goal.	The difference between setting parameters for personal goals and setting an overall goal was not clear enough in the protocol. This amendment provides clarity to

		recommends an overall goal.		guide the screening process.
July 17, 2017	Methods: Eligibility criteria – types of study designs, Table 1	In the original protocol, only systematic reviews are excluded.	The eligibility criteria for types of study designs is changed to exclude clinical guidelines as well.	Although clinical guidelines do not fit the inclusion criteria in the protocol, this amendment provides additional clarity to guide the screening process.
July 17, 2017	Methods: Eligibility criteria – types of participants, Table 1	We excluded studies where multiple cancer sites were studied and outcome data for females with breast cancer was not extractable.	We changed the eligibility criteria for types of participants to: include studies where females with breast cancer were one of multiple populations studied (other cancers, males with breast cancer, family members, etc), but outcome data for females with breast cancer were extractable; and exclude studies where females with breast cancer are one of multiple populations studied, but outcome data for females with breast cancer are not extractable.	This amendment provides additional clarity to guide the screening process.
July 27, 2017	Methods: Eligibility criteria – types of study designs, Table 1	Only systematic reviews are excluded.	We change the eligibility criteria for types of study designs to exclude case studies as well.	Case studies are difficult to distinguish from profiles or individual narrative stories. The potential benefits of inclusion – a wider mapping of the literature – were outweighed by the difficulties.
July 31, 2017	Methods: eligibility criteria – types of interventions/ exposures; 1st Amendment of July 17	In the protocol, we defined a major component of an intervention as: "The article's introduction should present a justification or theoretical basis for how goal-setting is expected to affect the outcome." A major variable is defined similarly in the amendment.	To determine whether goal-setting is a major component of an intervention or major variable of a study, the justification or theoretical basis should be presented in the article introduction or the methods section.	We find that interventions are often described in more detail in the methods section, and a justification may appear in that section instead.
July 31, 2017	First amendment of July 17 (to Methods: Eligibility criteria)	We stated that qualitative studies will be included if personal goal-setting is identified as a major variable (a justification or theoretical basis for how personal goal-setting is hypothesized to be related to other	We expand the definition of a major variable to include an alternative: that personal goal-setting is classified as a key theme in qualitative studies.	In qualitative studies, outcomes may not be pre-specified, and themes may not be apparent until after qualitative data is collected.

		study variables is presented in the article's introduction).		
July 31, 2017	Methods – selection process	There is no set process if a full-text article does not include enough information to make a decision at Stage 2.	If both Stage 2 reviewers agree that the full-text article does not include enough information about the participants, methods, interventions, or inclusion of personal goal-setting to make a decision about inclusion or exclusion, the study authors will be contacted to request more information. A maximum of two email attempts over two weeks will be made. If the necessary information be obtained from the authors, the study will be excluded and the reason documented.	This amendment provides additional clarity to guide the screening process.

Appendix 2 – List of Studies Excluded After Full-Text Review

Primary reason for exclusion	Study ID	
Data for study population could not be extracted	Bantum 2014	Lethborg 2006
	Beckmann 2007	Midtgaard 2012
	Demark-Wahnefried 2006	Miller 2016
	Hauken 2014	Rabin 2012
	Homsi 2002	Robb 2006
	Lauver 2007	Stetz 1994
	Lee 2006	
Duplicate	Davis 1995	Komatsu 2016
Full-text article could not be located or accessed	Angen 2003	Whyte 2004
	Cunningham 2002	
Not enough information to make decision about eligibility	Anderson 2015	Kvale 2016
	Hatchett 2013	
Personal goals not set by the participant	Barak 2012	Baumann 2017
	Cadmus 2009	Gokal 2016
	Courneya 2001	Harris 2013
	DeJesus 2017	Nagl 2012
	Fazzino 2016	Naumann 2012
	Gracey 2016	Ott 2004
	Hoy 2009	Paxton 2016
	Hunt-Shanks 2006	Phillips 2013
	Irwin 2008	Pinto 2005
	Kim 2011	Pinto 2013
	Lahart 2016	Pinto 2013
	Lee 2010	Reeves 2017
	Lee 2010	Rogers 2009
	Lee 2011	Rogers 2011
	Lee 2013	Rogers 2017
	Lee 2014	Sepucha 2012
	Matthews 2007	Tometich 2017
	Ng 2017	Vallance 2007
	Ottenbacher 2012	Vallance 2008
	Pinto 2008	Wilkinson 2012
	Pinto 2009	Wilson 2005
	Rogers 2013	
Personal goal-setting is not a major variable	Bahrami 2015	Kissane 2004
	Basen-Engquist 2006	Lechner 2014
	Bulmer 2012	Lee 2010
	Conlon 2015	McKiernan 2010
	Cunningham 1998	Midtgaard 2007
	Daley 2007	Morse 1995
	Dow 1994	Muraca 2011

Primary reason for exclusion	Study ID	
	Edelman 1999	Perna 2010
	Emslie 2007	Rock 2013
	Fergus 2014	Rosales 2014
	Franklin 2010	Scholten 2001
	Fu 2005	Scioli 2016
	Hawkins 2010	Stephen 2017
	Heidrich 2009	TimenesMikkelsen 2015
	Jensen 2000	Trinh 2014
	Kakai 2013	Vassbakk-Brovold 2017
	Kissane 1997	Weisenbach 2014
Study does not examine personal goal-setting	Antoni 2006	Mens 2016
	Ashing 2014	Milne 2008
	Braun 2005	Milne 2008
	Bright 2016	Mulero-Portela 2013
	Brunet 2011	Otto 2016
	Brunet 2013	Ozanne 2009
	Carpenter 2014	Pinto 2003
	Castonguay 2014	Rogers 2005
	Castonguay 2017	Ryhanen 2013
	Causarano 2015	Sabiston 2011
	Cheng 2010	Sepucha 2009
	Clough-Gorr 2009	Sheppard 2013
	Courneya 2008	Short 2014
	Danhauer 2007	Sivell 2012
	Donovan-Kicken 2010	Sivell 2012
	Dumontier 2017	Stang 2009
	Falzon 2015	Stang 2010
	Galiano-Castillo 2016	Stanton 2000
	Gordon 2014	Stanton 2002
	Hershman 2013	Stefanic 2015
	Ibfelt 2011	Thompson 2013
	Kang 2017	Whitehead 2009
	Lam 2016	Wojtyna 2007
	Lampic 2002	Wrosch 2013
	Lampic 2003	
Wrong language	Ascencio-Huertas 2013	Faller 2000
	Kroz 2016	Sebastian Herranz 1999
	황혜남 2016	
Wrong patient population	Bond 1958	Paraskeva 2017
	Care 2008	Ruiter 2003
	Paltiel 2009	
Wrong publication type	AlSaif 2014	Mark 2012
	Ananyeva 2012	Marquez 2008

Primary reason for exclusion	Study ID	
	Armer 2016	Martin 2011
	Armes 2011	Mathur 2011
	Barrere 1992	Melin 1996
	Bauer 2013	Merckaert 2005
	Block 2005	Metsker 2011
	Block 2006	Moon 2017
	Borovska 2014	Mori 2010
	Cheville 2005	Newman 2011
	Chung 2003	Paul 2017
	Clark 1989	Ramos 2013
	Daley 2004	Redemski 2016
	Desfalvi 2016	Roberts 2011
	Dolina 2014	Rojas-Espaillat 2014
	Edelman 1999	Rosales 2013
	Edelman 2000	Rubin 2009
	Fergus 2011	Saiki 2016
	Friborg 2005	Scheuer 2017
	Galiano-Castillo 2014	Simon 2006
	Gokal 2013	Solberg 2004
	Gregorio 2015	Spark 2012
	Grodzki 2011	Stefanic 2012
	Gryspeerdt 2011	Stefanic 2013
	Hartmann 2013	Stefanic 2016
	Henriksson 2014	Step 2014
	Irwin 2016	TenTusscher 2017
	Kracen 2014	Thornton 2009
	Kreitler 2015	Tjoe 2016
	Kuehn 2012	VanDenBerg 2011
	Laizner 2000	Ventura 2014
	Lapedis 2014	Wagner 2017
	Lawn 2013	Weis 2012
	Lechner 2012	West 2009
	Lindow 2012	Williams 2016
	Ludman 2016	Yildiz 2013
	Maheu 2015	
Wrong study design	Abrahm 2008	Hiroko 2016
	Dalton 1995	Hopko 2011
	Davis 1995	Ryan 2011
	Desiron 2016	Taplin 2015

Appendix 3 – TIDieR Checklists

Note: Some quotations from studies in column 3, "Quotation from study (page number)" include citations by the study authors. Cited articles can be found in the source articles. All quotations are from the article cited for the study unless otherwise indicated.

CHEUNG ET AL 2016[42]		
Item #	**Item description**	**Quotation from study (page number)**
1	**Brief name**	LILAC (lessons in linking affect and coping) p2
2	**Why**	*Intervention theory described in a cited article:* The intervention is based on revised stress and coping theory and the broaden-and-build theory of positive emotion. Folkman proposed a revision to Stress and Coping Theory that explicitly posits a role for positive affect in the coping process. According to the original theory, the coping process begins when an event is appraised as threatening, harmful, or challenging. These appraisals are associated with affect and prompt initial coping response. If the event is resolved favorably, a positive affective state is the result. If the situation is not resolved, or is resolved unfavorably, negative affect is the result. Chronic stress can be conceptualized as continued lack of resolution or unfavorable resolution that results in continued negative affect. The revised model suggests that the negative affect associated with chronic unfavorable resolution motivates coping processes that draw on important goals and values, including positive reappraisal and goal-directed problem-focused coping. These coping processes result in positive affect, which serves important coping functions: positive affect provides a psychological 'time-out' from the distress associated with chronic stress and it helps motivate and sustain ongoing efforts to cope with the negative effects of the chronic stress. Although not specific to stress, in the 'Broaden-and-Build' model the 'broadening' function of positive affect enables the individual to see beyond the immediate stressor and possibly come up with creative alternative solutions to problems. The 'building' function helps to rebuild resources (such as self-esteem and social support) depleted by enduring stressful conditions. In contrast to the narrowing of attention and specific actions tendencies associated with negative affect, positive affect broadens the individual's attentional focus and behavioral repertoire. Repeated experiences of positive affect build social, intellectual, and physical resources. p677[56]
3	**What (materials)**	*Facilitator script provided by author via email.* *No other materials described in article.*
4	**What (procedures)**	The intervention consisted of...sessions in which the participants learned 8 empirically based skills designed to increase the frequency of positive emotions...At each session, the participants were taught up to 3 of the skills and were asked to practice each skill as "home practice" every day until the next weekly session... Specifically, on the first 1 to 2 days of each week, the online-intervention participants were able to access an online lesson that introduced that week's skill(s) and were asked to complete their home practice between sessions. New lessons became available 7 days after beginning the previous lesson. p2
5	**Who provided**	The participants in the in-person intervention condition completed the sessions at UCSF with a trained facilitator, whereas the participants in the online-intervention condition received the same content delivered online through self-paced modules....The facilitators were experienced interviewers with backgrounds in community- based or public health research. The facilitators underwent extensive training (approximately 40 h of didactic and observational training specific to delivery of the intervention). p2

6	**How**	The participants in the online-intervention condition received the same content delivered online through self-paced modules… The participants in the in-person control condition also had 5 hourly one-on-one sessions at UCSF with the same trained facilitators as those in the intervention condition. p2
7	**Where**	The participants in the in-person intervention condition completed the sessions at UCSF [University of California, San Francisco] with a trained facilitator, whereas the participants in the online-intervention condition received the same content delivered online through self-paced modules. p2
8	**When and how much**	The intervention consisted of 5 weekly 1 hour sessions p2
9	**Tailoring**	*None described*
10	**Modifications**	*None described*
11	**How well (planned)**	The facilitator sessions were audiotaped and regularly reviewed by the project director to ensure adherence to the protocol. p2-3
12	**How well (actual)**	*Not described*

GRAVES ET AL 2003[43]		
Item #	**Item description**	**Quotation from study (page number)**
1	**Brief name**	New Directions
2	**Why**	Social Cognitive Theory SCT has been used to promote health behavior and enhance adjustment to chronic illness (see Bandura,1997, ch. 7). Lev (1997) provides a nice overview of the application of self-efficacy to oncology, noting that increasing self-efficacy can promote better adjustment to cancer. In addition to self-efficacy, two other elements of SCT may impact cancer patients' QOL and adjustment, outcome expectations and self-regulation… Successful psychosocial interventions for improving the QOL in breast cancer survivors appear to have elements that augment participants' coping self-efficacy, increase positive outcome expectations, and teach appropriate self-regulatory skills. Thus, implementing an SCT-based intervention with adult cancer survivors may provide maximum improvement of QOL outcomes… Description of Treatment Conditions Skill-Building Intervention Based on Social Cognitive Theory The experimental SCT-based skill-building intervention was conducted as an interactive and supportive group program with emphasis on information, skill building, practice, feedback, and enlistment of social supports. p122-5
3	**What (materials)**	Self-monitoring forms Table 1, p126 Copies of the treatment manual are available from the investigator. Footnote 1, p125
4	**What (procedures)**	The experimental SCT-based skill-building intervention was conducted as an interactive and supportive group program with emphasis on information, skill building, practice, feedback, and enlistment of social supports. The facilitator helped group members enhance their coping self-efficacy by teaching skills related to cognitive restructuring, relaxation, and assertive communication and then practicing these skills within a supportive environment...Group members were taught how to recognize and change

		negative outcome expectations into more positive expectations through cognitive restructuring techniques and discussion and setting of realistic goals. Self-regulation was encouraged by providing information for implementation of these skills outside of the group. Once women related their attempts of these skills, feedback was provided so that the participants could further improve the skills. New goals were set each week in accordance with the topic being discussed. p125 Description of intervention components (session number, session name, and session description) provided in Table 1, p126
5	**Who provided**	The investigator, a doctoral candidate in clinical psychology, facilitated one 8-week course of the SCT-based skill-building program, while a trained clinical psychology intern facilitated another 8-week course. p125
6	**How**	The experimental SCT-based skill-building intervention was conducted as an interactive and supportive group program...Women assigned to the intervention (n=15) attended the program in small groups. p125
7	**Where**	*Not described*
8	**When and how much**	The 8-week intervention was conducted once a week for 1 1/2 hours each session. p125
9	**Tailoring**	Sessions included information tailored to individual group participants and their current level of functioning. p125
10	**Modifications**	*None described*
11	**How well (planned)**	*Not described*
12	**How well (actual)**	*Not described*

HARCOURT ET AL 2016[44]		
Item #	**Item description**	**Quotation from study (page number)**
1	**Brief name**	PEGASUS (Patients' Expectations and Goals: Assisting Shared Understanding of Surgery) p249
2	**Why**	Women's dissatisfaction often relates to pain and scarring and has been associated with expectations of surgical outcome or process. However, their expectations are often unclear. Therefore, clarifying patients' expectations, preferences and values is key. Active patient involvement through shared decision-making is associated with more positive patient experiences and outcomes, particularly' preference-sensitive' decisions like those about breast reconstruction. Several breast surgery decision aids are available, but clinicians report concerns that they are not tailored to individual needs, could replace nurses' roles or induce patient anxiety. Recently, attention has shifted to decision coaching to facilitate patients' preparations for shared decision-making about preference-sensitive decisions. PEGASUS (Patients' Expectations and Goals: Assisting Shared Understanding of Surgery) aims to elicit expectations of reconstruction, to aid discussion and setting of patient-centred goals. p248-9
3	**What (materials)**	A psychologist helps the patient identify her individual goals for surgery and what she considers indicative of a successful outcome. These are summarized and the patient rates each goal (from 0 to 10) in terms of its importance. This takes around 45 min. The PEGASUS sheet is then used in the surgical consultation to set shared goals and promote concordance between the patient and surgeon. p249
4	**What (procedures)**	A psychologist helps the patient identify her individual goals for surgery and what she considers indicative of a successful outcome. These are summarised and the patient

		rates each goal (from 0 to 10) in terms of its importance. This takes around 45 min. The PEGASUS sheet is then used in the surgical consultation to set shared goals and promote concordance between the patient and surgeon. The surgeon rates the probability of achieving each patient-set goal (from 0 to 10), thus facilitating discussion about whether expectations are realistic, before final decisions about surgery are made. p249
5	**Who provided**	A psychologist helps the patient identify her individual goals for surgery...The surgeon rates the probability of achieving each patient-set goal (from 0 to 10), thus facilitating discussion about whether expectations are realistic, before final decisions about surgery are made. p249
6	**How**	Eligible women were...invited to an appointment where the PEGASUS intervention...took place. p249
7	**Where**	This study was conducted in a large NHS [National Health Service] hospital offering breast reconstructive procedures. p249
8	**When and how much**	Eligible women were identified from clinic lists, sent the study information and invited to an appointment where the PEGASUS intervention (outlined above) took place....It is provided after a woman has received information about her specific surgical options. p249
9	**Tailoring**	*None described*
10	**Modifications**	*None described*
11	**How well (planned)**	*Not described*
12	**How well (actual)**	Patient interviews indicated that the PEGASUS sheet was used according to the intervention protocol in 9/12 consultations. However, three women thought that the surgeon paid little attention to the PEGASUS sheet or seemed unsure how to use it p252

HEGEL ET AL 2011[45]		
Item #	**Item description**	**Quotation from study (page number)**
1	**Brief name**	Problem-solving Treatment-Occupational Therapy (PST-OT) p1092
2	**Why**	Most breast cancer patients experience functional limitations while undergoing cancer treatment [1]. These limitations interfere with roles that they value in their daily lives, known as 'participation restrictions' (i.e. instrumental activities of daily living, social, work, and leisure activities) [5]. Participation restrictions during treatment not only affect quality of life but may also lead to enduring restrictions long after cancer treatment has ended [6]…Overcoming participation restrictions and adhering to self-directed rehabilitation programs, therefore, may not be possible without addressing environmental and practical barriers. Addressing such barriers falls within the realms of problem solving therapies [19] and occupational therapy interventions [20]; however, such interventions have not been tested for this purpose in breast cancer survivors undergoing chemotherapy…To address these issues, we designed a telephone delivered problem-solving and occupational therapy intervention (PST-OT) to assist rural breast cancer patients undergoing adjuvant therapy to reduce participation restrictions in valued areas (e.g. self-care, work, social, and leisure activities), and promote adherence to activities that support this task (i.e. aerobic exercise, upper extremity physical therapy, and stress management). Theoretically, the PST-OT intervention is derived from a self-regulation perspective of disability and adaptation [21]. Disability represents a discrepancy between the person's intrinsic capabilities and demands of the environment [22]. Adaptation involves reducing this discrepancy [23]…A key modification for the new PST-OT intervention was the integration of the Person, Environment, Occupation Model (PEO) of occupational therapy into the brainstorming stage of problem solving [26]. In the PEO model, the term 'occupation' refers to 'valued activities,' which are the meaningful and

		purposeful activities that occupy one's time, contribute to one's identity and community, and reflect one's culture. p1092-3.
3	**What (materials)**	The OT was trained by the principal investigator, which included reviewing the treatment manual adapted from our previous research [27]...The PST-OT patient manual contained a lay description of the problem-solving process, worksheets to be used during PST-OT treatment sessions, guidelines for energy conservation to address fatigue, and a compact disc with a progressive muscle relaxation (PMR) exercise personally recorded by the OT....The OT used a structured worksheet to lead the participant through a PST-OT treatment session...p1094
4	**What (procedures)**	At the beginning of session 1, the rationale for testing PST-OT for reducing participation restrictions during chemotherapy was explained. The OT then reviewed the participation restriction survey with the participant to identify activities that were rated as at least moderately important and that had at least a moderate level of difficulty. These activities became the targeted problem areas for PST-OT sessions. The OT used a structured worksheet to lead the participant through a PST-OT treatment session, which followed seven steps: (1) exploration, clarification, and definition of the participation restriction; (2) setting a goal that was objective, behavioral, and achievable; (3) brainstorming alternative solutions, guided by the PEO model, without judgment of the solutions; (4) decision analysis of each solution to evaluate their feasibility (i.e. the amount of effort, time, cost, emotional impact on self or others, and the need to involve other people in the solution); (5) choosing a solution that was feasible and that carried limited negative impact on the participant or others; and (6) implementing the solution (or action plan) by identifying the specific steps to be completed (e.g. where, when, how, with whom). In PST-OT, the goal, solutions, and action plans came from the participant as the best judge of their own situation. / The last task of the first and each subsequent session was for the OT to remind the participant to engage in aerobic exercise, stress management using the PMR CD, and upper extremity exercises if indicated (all breast cancer patients received a physical therapy evaluation and recommendations for home-based therapy as part of their routine care). If the participant was experiencing difficulties with these programs, they were targeted in PST-OT sessions. / Sessions 2–6 began by completing the seventh step of problem solving, that is evaluating the outcome of the action plan. Depending on the outcome the OT then asked the participant if they wished to continue working on the previous participation restriction or to address a different restriction. During each session, the entire seven step problem-solving procedure was applied for at least one participation restriction or healthy behavior. p1094
5	**Who provided**	A licensed occupational therapist (OT) conducted all treatment sessions (KL). The OT was trained by the principal investigator, which included reviewing the treatment manual adapted from our previous research [27], and role play sessions with experienced oncology nurses. p1094
6	**How**	The first telephone-delivered PST-OT session was conducted within 1 week of the baseline assessment and subsequent sessions were provided on a weekly basis for 6 weeks. p1094 *Individually delivered - descriptions of the intervention refer to the "participant" in the singular*
7	**Where**	*Distance - telephone-based intervention*
8	**When and how much**	The first telephone-delivered PST-OT session was conducted within 1 week of the baseline assessment and subsequent sessions were provided on a weekly basis for 6 weeks… The mean length of the first session, which included providing the treatment rationale, discussing the range of participation restrictions, and conducting a full PST-OT session, was 71 min (SD=16 min). The mean length of the follow-up sessions (sessions 2–6), which included only a PST-OT session was 35 min (SD=13 min)…Of the 10 PST-OT participants remaining after the early withdrawals, 62% completed their treatment within the 6-week window targeted in the protocol (i.e. 6 weekly sessions). The remainder (38%) completed all sessions in 7 weeks. p1094, 1096-7
9	**Tailoring**	If the participant was experiencing difficulties with these [activity] programs, they were targeted in PST-OT sessions. Sessions 2–6 began by completing the seventh step of problem solving, that is evaluating the outcome of the action plan. Depending on the

		outcome the OT then asked the participant if they wished to continue working on the previous participation restriction or to address a different restriction...In later sessions, if most of the obstacles to the targeted participation restrictions had already been addressed, sessions occasionally consisted primarily of refining goals and action plans rather than completing each step of PST-OT. p1094
10	**Modifications**	*None described*
11	**How well (planned)**	The first author supervised the OT throughout the course of the study via review of session audiotapes using a standardized treatment fidelity scale [28] and weekly meetings. p1094
12	**How well (actual)**	*Not described*

LYONS ET AL 2015[46]		
Item #	**Item description**	**Quotation from study (page number)**
1	**Brief name**	Behavioral activation/ problem-solving (BA/PS) intervention
2	**Why**	While quality of life generally improves after completion of breast cancer treatment (Deshields et al., 2005), 10% to 23% of women experience reduced quality of life over the year after breast cancer treatment (Penttinen et al., 2011). That reduced quality of life is often associated with a reduction in activity level…Egan and McEwen (2013) noted good evidence supporting the use of exercise and other physical rehabilitation techniques to improve physical function, but an absence of research on interventions that encourage satisfying role resumption and full participation in valued daily activities. To address this gap, we developed a brief, telephone-based intervention and pilot tested it with breast cancer survivors across two studies. The intervention was based on principles of two cognitive-behavioral therapies: behavioral activation (BA; Cuijpers, van Straten, & Warmerdam, (p200) 2007a; Lejuez, Hopko, LePage, Hopko, & McNeil, 2001) and problem-solving treatment (PST; Cuijpers, van Straten, & Warmerdam, 2007b; Hegel & Arean, 2003). Participants used the goal setting and problem-solving structure of the behavioral activation/problem-solving (BA/PS) intervention to address challenges in many areas of life, including getting exercise, managing stress, and functioning better at work and home…BA (Cuijpers et al., 2007a; Lejuez et al., 2001) and PST (Cuijpers et al.,2007b; Hegel & Arean, 2003) are two manualized, evidence-based interventions originally designed to treat depression... Although they were initially designed to treat depression, we believe the pragmatic and activity focused nature of both BA and PST offer accessible, structured frameworks with which to address a variety of functional challenges faced by cancer survivors. p201-2
3	**What (materials)**	The women received a workbook that contained background information and worksheets that they used to set and monitor weekly goals. p204 The aims of the first study were to develop the treatment manual...The aims of Study 2 were to revise the treatment p201 manual p201-2
4	**What (procedures)**	We blended BA and PST into our BA/PS intervention...The BA process involved four steps: (1) identifying why an activity was challenging, (2) setting a goal that was behavioral, measurable and achievable within the next seven days, (3) constructing a detailed action plan that delineates when, where, and how the activity will be conducted, and (4) assessing how well the goal was met and the activity was performed. Problem-solving adds two additional steps to this process…During the first session the interventionist explained the rationale for the study, discussed the relationship between activity engagement and health, reviewed the benefits of regular exercise and effective stress management techniques, and explained the structure of BA/PS...During the first session we asked women to tell us about their cancer treatment and how satisfied they felt with their engagement in the above-listed activity domains. p202-4

5	**Who provided**	Study 1: Interventionist=1st author. Study 2: We hired an interventionist who was available to deliver the intervention by telephone at participant's convenience (day or night of all weekdays). p202 *Training of interventionists referred to in passing:* While we were able to train two different people to do the intervention, the findings of each study… p215
6	**How**	We delivered the intervention via telephone. p201
7	**Where**	*Distance – by telephone*
8	**When and how much**	The intervention consisted of nine telephone-delivered sessions that occurred once a week for 6 weeks, with three monthly follow-up sessions. p201 Of the 67 completed sessions for Study 2, 19 occurred in the morning (28%), 37 in the afternoon (55%), and 11 in the evening (17%). The first sessions averaged 76 minutes in length (SD = 15) and the subsequent sessions averaged 36 minutes in length (SD = 18). p211
9	**Tailoring**	If a goal is very general and a woman is unsure of how to meet her goal, she is prompted to (1) brainstorm various solutions and (2) weigh their advantages and disadvantages before selecting one and proceeding to develop an action plan. p203-4 The first step of each subsequent session [after Session 1] was to review how well the previous action plan worked, how satisfied the woman was with the effort she put into executing her action plan, and whether the goal was met. The woman could then choose to address the same goal(s) for the coming week or could identify new activities to address with BA/PS. p204 In Study 1, all sessions used behavioral activation alone. In Study 2, 85% of the goals were set using behavioral activation alone, while problem-solving was added to behavioral activation to set 15% of the goals. p211
10	**Modifications**	*In Study 2* To improve the intervention, we created an explicit decision rule regarding when to utilize the problem-solving process (described in the next section). We hired an interventionist who was available to deliver the intervention by telephone at participant's convenience (day or night of all weekdays) and reduced the intervention to six weekly sessions. We used the same feasibility and acceptability metrics as Study 1, but incorporated some new outcome measures. p202
11	**How well (planned)**	Sessions were audio recorded for the purposes of fidelity monitoring and intervention development. We monitored the fidelity of the interventionists to the developing treatment manuals in two ways. In Study 1, the p204 principal investigator (last author) met at least monthly with the interventionist to discuss the challenges and pragmatics of delivering the intervention. He also formally rated interventionist fidelity on seven randomly chosen sessions from four participants using a 10-item scale developed for other studies of behavioral activation. In Study 2, the principal investigator and interventionist (first author) met weekly to discuss the study and the intervention development process. They developed a 17-item scale that reflected the BA/PS intervention tasks and a psychologist (fifth author) trained in both behavioral activation and problem-solving treatment used the scale to rate 20 sessions (a first session and a randomly chosen subsequent session from 10 participants). p204-5
12	**How well (actual)**	In both studies, all rated sessions met the performance standards set by the fidelity rating systems. p205

NÁPOLES ET AL 2015[47]		
Item #	**Item description**	**Quotation from study (page number)**

<table>
<tr><td>1</td><td>Brief name</td><td>Nuevo Amanecer (New Dawn)</td></tr>
<tr><td>2</td><td>Why</td><td>Social-cognitive theory served as the conceptual framework for the intervention. pe57</td></tr>
<tr><td>3</td><td>What (materials)</td><td>The Nuevo Amanecer program and its development are described in detail elsewhere.[21,22] pe56

From cited article:

The final Nuevo Amanecer program is an individualized Spanish-language 8-week intervention that emphasizes cognitive-behavioral coping skills to manage stress and emotions. It includes emotional support, informational resources, training in selfcare behaviors, and modeling provided by compañeras using a structured program manual (Table 1). p233[57]

Table 1. Contents of the Nuevo Amanecer program: a cognitive-behavioral stress management intervention for Spanish-speaking Latinas with breast cancer p234[57]
<table>
<tr><th>Intervention modules</th><th>Content</th></tr>
<tr><td>Week 1 – Managing the initial impact of cancer</td><td>Common reactions to a cancer diagnosis, signs of depression, tracking symptoms, deep breathing, breast cancer, and breast cancer diagnostic tests</td></tr>
<tr><td>Week 2 – Finding the cancer information you need</td><td>Cancer treatment team members, communicating needs to clinicians, effective communication skills, asking for a professional medical interpreter, breast cancer treatments, participating in and making treatment decisions, calling the National Cancer Institute’s Cancer Information Service</td></tr>
<tr><td>Week 3 – Getting the support you need</td><td>Effect of a cancer diagnosis on family members and friends, talking about cancer with others, good communication skills, dealing with criticism, identifying sources of support, asking for help when needed, and faith and prayer</td></tr>
<tr><td>Week 4 – Thoughts and mood: part I</td><td>Identifying thoughts, effects of thoughts on mood, distinguishing between unhelpful and helpful thoughts, ways to replace unhelpful thoughts with helpful thoughts</td></tr>
<tr><td>Week 5 – Thoughts and mood: part II</td><td>Decreasing unhelpful thoughts, increasing helpful thoughts</td></tr>
<tr><td>Week 6 – Stress management</td><td>Identifying stress and its causes, healthy and unhealthy ways to manage stress, three techniques for handling stress (avoid, change, and adapt situations), low-intensity ways to reduce stress (deep breathing, engaging in joyful activities, guided imagery), using coping statements</td></tr>
<tr><td>Week 7 – Setting goals: part I</td><td>Managing activities, increasing pleasant activities, use of laughter, distraction techniques, goal setting</td></tr>
<tr><td>Week 8 – Setting goals: part II</td><td>Review of finding cancer information, communicating with family and clinicians, increasing helpful thoughts, stress management</td></tr>
</table>
Compañeras were provided with a step-by-step Spanish-language manual covering the 8-week program sessions. p234[57]</td></tr>
<tr><td>4</td><td>What (procedures)</td><td>Eight weekly modules covered managing the initial impact of cancer, finding cancer information, getting support, identifying helpful and unhelpful thoughts, managing thoughts and mood, stress management techniques, managing activities that affect mood, and goal setting. pe57

Each of the 8-week sessions includes an overview, a review of the prior session, content for that week, interactive activities, time for participants to restate the main concepts in their own words, homework, and a session recap p233[57]</td></tr>
<tr><td>5</td><td>Who provided</td><td>The program was delivered by trained compañeras (companions). Compañeras were bilingual or Spanish-monolingual Latina breast cancer survivors who had completed active treatment and were at least 3 years post diagnosis with no recurrence.</td></tr>
</table>

		Compañeras participated in 3 consecutive 8-hour training sessions conducted by academic and community partners. pe57
6	**How**	The Nuevo Amanecer program was delivered face to face in participants' homes. pe57
7	**Where**	The Nuevo Amanecer program was delivered face to face in participants' homes. pe57
8	**When and how much**	Eight weekly modules...Each week, one 90-minute module was presented using visuals and hands-on exercises to teach and reinforce concepts and skills. pe57
9	**Tailoring**	*None described*
10	**Modifications**	*None described*
11	**How well (planned)**	*Not reported*
12	**How well (actual)**	*Fidelity was measured during development of the intervention, described in a different article:* We tracked several measures of fidelity, defined as the adequacy of delivering the intervention as designed. Compañeras tracked the date, mode, duration, nature, and outcome of each call or visit using structured tracking forms and collected weekly homework. The community Co-PI randomly selected two sessions for each compañera which she observed and audio-recorded. She rated sessions using a structured rating scale that assessed the extent to which compañeras accurately delivered the intervention. Two independent observers listened to and rated audiotaped sessions using the same rating scale. p236[57]

WILJER ET AL 2013[50]		
Item #	**Item description**	**Quotation from study (page number)**
1	**Brief name**	SC (Survivorship Consult)
2	**Why**	The SC is a 1-h self-reflective interview, structured based on combined elements of the City of Hope survivorship framework [27], the IOM 2006 Lost in Transitions and several disease management frameworks [2, 28–30]. p2119
3	**What (materials)**	This [developing an individualized plan] is done through a collaborative process with a supportive care clinician and the survivor using eCancer as the primary tool that allows for standardizing the SC, as well as providing consistent resources to survivors. eCancer is an online platform for synoptic reporting which generates the clinic note for the survivor's chart in real time. The SC is a series of online forms which live and are delivered to supportive care clinicians providing SC through the eCancer platform. During an SC, the supportive care clinician is able to populate the fields of the appropriate SC form, summarize the survivor's treatment history and creates a natural language clinic note in real time. Using this tool, survivors are provided with appropriate support, education and information that they can incorporate throughout their treatment. p2119
4	**What (procedures)**	The initial SC...involves a review of the survivors' understanding of their BCa trajectory to date, the treatments received and proposed, their available support systems and their survivorship needs and goals…Based on individual needs, goals and priorities, the survivor and clinician collaborate to develop an individualized plan that will meet the physical, social, emotional and spiritual needs of the survivor. This is done through a collaborative process with a supportive care clinician and the survivor. p2118-9

5	**Who provided**	It is conducted by a supportive care clinician, usually a social worker, nurse or psychologist. The SC has been designed to be delivered in inter-professional practices and clinicians from each of these disciplines are trained to deliver the SC. These clinicians are part of a Survivorship Clinic, and they do not replace the role of the core clinical team. The clinicians are dedicated staff in the Survivorship Clinic, and they refer the patient back to the treatment team to address any treatment related issues. p2119
6	**How**	*In-person*: The initial SC is usually conducted during the first visit to the BCSP p2118 *No other details reported*
7	**Where**	At Princess Margaret Cancer Centre (PMCC), survivorship care is provided through the Breast Cancer Survivorship Program (BCSP)...The initial SC is usually conducted during the first visit to the BCSP. p2118
8	**When and how much**	The initial SC is usually conducted during the first visit to the BCSP…The SC is a 1-h self-reflective interview…If possible, the Consult is provided from the point of diagnosis, 3–6 months into treatment and long after active treatment has finished (approximately 1 year). These time points correspond with periods of change and uncertainty along the trajectory of care and SC at these times serves as an important guide and reinforcement of self-management throughout the trajectory. Survivors are given the option to have additional, more frequent 30-min follow-up SC, even after they are 1 year post-treatment. p2118-9
9	**Tailoring**	Based on individual needs, goals and priorities, the survivor and clinician collaborate to develop an individualized plan that will meet the physical, social, emotional and spiritual needs of the survivor. p2119
10	**Modifications**	*None described*
11	**How well (planned)**	*Not reported*
12	**How well (actual)**	*Not reported*

WILJER ET AL 2010[51]		
Item #	**Item description**	**Quotation from study (page number)**
1	**Brief name**	SC (Survivorship Consult)
2	**Why**	The SC is based on the assumption that the most effective means for eliciting a desire to engage in self-management practices involves collaborative goal setting and treatment planning [26].…To ensure a systematic approach, the SC is guided by a templated interview that is organized according to the City of Hope framework [3] and divided into sections that encompass the four identified domains of wellness.p459, 461
3	**What (materials)**	Helping to structure this process is an electronic tool known as eCancer for Breast Cancer Survivorship Care (eCBCSC), which uses an easy, click-box approach to collect, organize, and present clinical data through a common, pictorial view of the patient experience...The information gathered is integrated into a synoptic report that can be generated two different ways: a summary note specifically designed for the clinician that is sent automatically to the central electronic chart, and a treatment summary and care plan that is given to the patient that can be printed in a hard copy outlining key clinical data and summarizing goals and actions to achieve these goals. p459
4	**What (procedures)**	The SC is a reflective interview that focuses on obtaining a snapshot of the combined challenges facing the breast cancer survivor and identifying possible management strategies to address these concerns...During the initial SC, the survivor and clinician work collaboratively to formulate an individualized action plan that will address the survivor's information, education, and support needs. Survivors are then orientated to appropriate services, including educational classes or programs and clinical services,

		as well as community programs and resources. Survivors can return to the BCSP 6–12 months later for a follow-up. p458
5	**Who provided**	Currently conducted by either a social worker or psychologist. p458
6	**How**	*In-person*: The initial SC is conducted during the first visit to the BCSP…p459 *No other details reported*
7	**Where**	The initial SC is conducted during the first visit to the BCSP…p459
8	**When and how much**	The initial SC is conducted during the first visit to the BCSP…p459
9	**Tailoring**	The focus of the SC is on tailoring the intervention to the individual's experience and unique needs. p461
10	**Modifications**	*None described*
11	**How well (planned)**	*Not reported*
12	**How well (actual)**	*Not reported*

Appendix 4 – Study Results Related to Personal Goals and Interventions

Number and characteristics of personal goals

Nine studies (in eleven articles) presented goal-related results.[17,42-45,47-49,52,53] Four of the nine studies, including Sullivan-Singh 1, reported either or both the total number of goals set by all participants (range 79 – 141) and the average number of goals set per participant (range of means 2.56 – 6.52).[17,43,48,52] One of the nine studies included goal importance ratings: more than three-quarters of the goals were rated 9 or 10 out of 10 (higher ratings indicate higher importance).[44] Six of the nine studies (in seven articles), including Sullivan-Singh 1, reported results related to goal content, specifically thematic groupings of goals:[17,44,46,48,49,52,53] two presented goal content using the goal as the unit of analysis (e.g. four goals classified as "to not restrict physical activity"),[44,49] one used the participant (e.g. three participants identified goals classified as "exercise"),[53] one (in two articles) used both units of analysis,[46,52] and two did not specify whether results were analyzed by participant or goals.[17,48] Methods used to categorize goal themes also varied. Sullivan-Singh 1 used Socioemotional Selectivity Theory to guide the selection of their goal content categories,[49] two studies specified that goals were categorized using the wording of the goals set,[52,53] and the remaining studies did not specify how categories were determined.

Each study had specific parameters for goals, making it difficult to compare goal themes across studies. For example, Harcourt et al asked participants to identify their goals for surgery; many common goal themes were related to appearance and social well-being (e.g. looking "normal", feeling "normal, like other women").[44] In two other studies, the authors asked participants to set goals for activities that were personally challenging but important, observable and achievable; in those studies, the most common activities targeted by the goals were: exercise,

work, activities of daily living (e.g. house cleaning), nutrition, and stress.[52,53] Of the two studies that quantitatively measured participant ratings of a goal characteristic (i.e. importance), only Harcourt et al presented the related results.[17,44] Five of the nine studies (in six articles) reported results related to goal development or progress.[17,46,48,50,52,53] Two studies (three articles) reported quantitative goal attainment results, with only Searls and Fawcett measuring participant assessments.[46,48,52] One study reported the kinds of adaptive strategies used by study participants to facilitate goal attainment;[53] one reported the intervention processes that were used to plan for goal striving and reported on participant satisfaction with goal pursuit efforts;[52] one reported cancer-related goal interference between groups and over time;[17] and one reported qualitatively on the effects of goal-setting on motivation for goal pursuit.[50] One study also categorized reasons for unmet goals in their study.[52] Goal-related results are summarized in Table 3.

Three of the nine studies presented results on associations between variables related to goals set in the study and other variables.[43,49] Sullivan-Singh 1 categorized goals set (yes/no) in terms of time perspective (i.e. limited time perspective such as enjoying the present; expansive time perspective such as planning for the future). Sullivan-Singh 1 then presented associations between select demographic or medical variables (age, marital status, metastatic cancer status, and time since metastatic diagnosis) and the presence of a given time perspective dimension.[49] Sullivan-Singh 2 presented associations between having goals with particular time perspective dimensions and psychological adjustment (i.e. cancer-specific stress and perceived cancer-related benefits).[49] Graves et al measured goal-setting as one of five domains of outcome expectations and presented the association between the outcome expectations related to goal-setting behaviour (higher scores indicated more positive outcome expectations) and quality of life.[43]

Intervention-related results

One study was a randomized controlled trial that examined the effect of the intervention on quality of life and distress (general and breast cancer-related).[47] The other seven studies were pilot or feasibility studies which presented results related to the efficacy or effectiveness of the intervention.[42-46,50,51] All but one[43] of the pilot or feasibility studies presented results on the feasibility or acceptability of the intervention. Relevant intervention effects or results are presented in Table 4.

Chapter 4: Personal goals of women recently diagnosed with breast cancer: Protocol for a cohort study (Manuscript #3)

Chow AJ, Fergusson DA, Seely D, Young S, Pitman A, Ennis J, Asad S and Presseau J. Personal goals of women recently diagnosed with breast cancer: Protocol for a cohort study. University of Ottawa Journal of Medicine. Dec 2017; 7(2): 34:41.

4.1 PROLOGUE TO CHAPTER 4

As discussed in the previous chapter, very few published studies have examined personal goal-setting among women with breast cancer. In my scoping review, I identified only 12 studies, most published within the past decade and employing a variety of methodologies. In this nascent field, only two studies examined personal goal-setting among Canadian women with breast cancer.

In this chapter and the next, I present a protocol and conduct of a cohort study I performed on the personal goals of women with breast cancer in Ottawa, Canada. This cohort study examines goal-setting with a subset of women living with breast cancer for which there is a lack of published research on personal goal-setting: women recently diagnosed with breast cancer (less than six months since diagnosis).

In my scoping review, I found that there was also a lack of published studies that quantitatively measured participant-rated characteristics of personal goals among women with breast cancer. No study measured any characteristic besides goal importance (other possibilities include, for example, likelihood of success or how challenging a goal is). Personal goal-setting is an idiographic exercise – i.e. goals are highly personal, conceptualized and articulated in ways unique to the individual. Quantitative, standardized measures allow researchers to make comparisons across the highly unique domain of personal goal-setting. Such measures have been incorporated into my cohort study.

4.2 ABSTRACT

Objectives: This study aims to identify the personal goals of women with breast cancer, to describe the characteristics of participants' personal goals over four months, and to identify barriers and facilitators to their pursuit.

Methods: This protocol outlines plans to conduct a prospective cohort study. We will recruit women participating in the Ottawa Integrative Cancer Centre's Head Start program (an integrative oncology psychoeducational program in Ottawa, Canada), and those on the program's waiting list if possible. We anticipate a sample size of approximately 18 to 36 women. At baseline (prior to the beginning of Head Start), participants will identify their current personal goals and rate them on various dimensions on a questionnaire. At one and three months, participants will re-assess their goals and their goal pursuit. In a one-on-one interview at three months, they will identify barriers and facilitators to the pursuit of their goals. We will analyze quantitative data using descriptive and inferential statistics, and qualitative data using thematic content analysis.

Conclusion: Findings from this study will identify important information about the personal goals of women recently diagnosed with breast cancer that can help to support the process of positive goal adjustment and enhance support to these women.

4.3 INTRODUCTION

Everyday life is characterized by the pursuit of multiple personal goals, such as learning to salsa dance or spending more time with family, which together describe important expressions of life motivations.[1] A *personal goal* is an individual's cognitive expression of a desired state or process which provides directional motivation towards that state; it defines what individuals do and strive for in everyday life.[2,3] Goals may be described at various levels of aggregation.[2] For example, *personal strivings* are mid-level goals, which often become the inputs of higher-order goals and life meaning.[2,4] Trying to always say hello to the coffee shop clerk facilitates the higher-order goal of being a good person. *Personal projects,* a closely related term, are also mid-level, individually defined, characterized by action and shaped by an individual's environment.[5-7] For consistency, we use the term *personal goals* in the sense of personal projects and personal strivings. Goal-setting theory suggests that conscious goal-setting and motivation is important in determining individual performance and satisfaction.[8] Diagnosis with a serious illness such as cancer, however, can affect an individual's day-to-day physical resources and time, thus disrupting the pursuit of personal goals.[9-11] Among women with breast cancer, a higher burden of physical symptoms has been associated with a reduced ability to pursue goals, and higher psychological distress.[12] Reducing physical symptoms or distress are common reasons that women with breast cancer seek complementary therapy.[13] Over the past decade, an approach known as integrative oncology, which integrates evidence-based complementary therapies and medical treatment, and emphasizes patient-centered care and coordination between providers, has emerged.[14] The Ottawa Integrative Cancer Centre (OICC) practices integrative oncological care, treatment, and research. With community support, the OICC developed and operates the Head Start program, to address the distress expressed by many of their clients recently diagnosed with breast cancer. Funded by Babes4Breasts and free of charge to participants, Head Start offers education, resources, and skills

to improve women's knowledge of integrative care options, reduce fear and anxiety, and strengthen their ability to cope with their diagnosis and incorporate life changes associated with living well with cancer.

A study of personal goals, expressions of life motivations, among women with breast cancer aligns with integrative oncology's focus on patient-centered care. In our literature search, we identified one published study of personal goals in integrative oncology.[15] Participants in an integrative oncology program in Vancouver, B.C. were asked to identify personal goals related to program participation. The personal goals identified highlighted important motivations related to breast cancer: improved well-being, increased chance of remission, increased physical energy, more effective pain management, and a return to active living.[15] But to design effective interventions that help women with breast cancer set and successfully pursue their goals, we first need to understand whether this population is able to pursue their goals, and what factors may facilitate or obstruct that pursuit. In partnership with the OICC, we plan to examine in depth the personal goals of women participating in the Head Start program. Our primary objective is to identify the perceived barriers to and facilitators of goal pursuit, including those related to Head Start. The secondary objectives are to describe the characteristics of participants' personal goals (goal content and dimensions) over time, and to analyze whether women pursue their most important goals. Goal dimensions are factors which express how women think or feel about their goals (e.g. difficulty, control).[2] They can be associated with important outcomes: higher goal importance may be associated with better psychological outcomes among people living with cancer, and higher goal stress with worse depressive mood and worse subjective health.[10,16] Towards their program objectives, Head Start works with women on mindfulness, awareness of emotions, identifying social supports and use of coping mechanisms. Based on the aims and activities of Head Start, we hypothesize that there will be an increase in ratings of self-identity,

perceived autonomy, and perceived support from others. In addition, we hypothesize a decrease in feelings of being scared and stressed over time among Head Start participants that will be greater than changes observed within the control group.

4.4 METHODS

4.4.1 Study design

This will be a prospective, observational cohort study of women participating in the OICC's Head Start program and, if available, controls taken from the program's waiting list ("wait-list controls").

4.4.2 Participants and procedures

Eligible individuals must be: either enrolled in one of two upcoming Head Start rounds (May and September 2017), or placed on a waiting list for either of these rounds; aged 18 years or older; female; and experiencing their first cancer diagnosis. They must also have good English comprehension and received a breast cancer diagnosis no more than five months prior to the start of the Head Start round for which they are enrolled or on the waiting list. Participants who are unable to provide informed consent will be excluded.

Recruitment will take place one to fourteen days prior to the first day of each Head Start round. The exposure, participation in Head Start, will last approximately five weeks. For each round, data will be collected at three time points: approximately one to fourteen days prior to Head Start (T1 - baseline); approximately one week after Head Start ends (T2); and approximately two to three months after Head Start ends (T3). Study procedures are illustrated in Figure 1.

Ethics approval was obtained from the Research Ethics Boards of the Ottawa Hospital Science Network (OHSN-REB) and the Canadian College of Naturopathic Medicine. Participants

will provide written informed consent consistent with the OHSN-REB's guidelines before taking part in the study.

4.4.3 Recruitment

The OICC will conduct recruitment. Following OICC standard procedure, interested individuals will be assessed for eligibility for Head Start. Eligible women will enroll or be placed on a waiting list if maximum enrollment has been reached. If a woman also meets this study's eligibility criteria, the OICC will inform her of the study. Interested individuals will receive a letter of introduction about the study and the consent form. Study enrollment and consent will be conducted by the primary investigator (the first author). Recruitment started in May 2017.

4.4.4 Sample size

The anticipated sample size will be 18 to 36, but will depend on the number of women interested in participating in selected Head Start rounds and the availability of a control cohort. This study is primarily concerned with examining the goals of Head Start participants, the "exposed" group. A control cohort will be included only if the following criteria can be met. If maximum enrollment (12 women) in each Head Start round is reached, the OICC places additional eligible individuals on a waiting list. If a minimum of 12 women on the waiting list enroll in this study, a control cohort will be formed. Based on our expectation of the Head Start enrollment process, the "exposed" group will have a maximum of 24 individuals (2 rounds of 12 individuals).

4.4.5 Data elements and instruments

Data sources and assessment methods are summarized in Table 1. We will invite participants to complete paper-based questionnaires at T1, T2 and T3 (15 to 25 minutes to complete each). At T3, following completion of the questionnaire, participants will participate in a

face-to-face, one-on-one interview (approximately 45 minutes), audio-recorded following participant consent.

Head Start participation

The exposure is Head Start participation: enrollment and attendance in a pre-specified Head Start round (yes/no). Non-participants will be on the waiting list to participate in Head Start, thus forming the wait-list control group for this study. If a spot becomes available in Head Start prior to the first day of the round and a wait-list control becomes a participant in Head Start, she will be included in the "exposed" cohort rather than the control group. Crossover is not possible after the program starts. We will count the days of Head Start participation in the exposed group using OICC attendance records linked to study records.

Personal goals

To identify personal goals, we will use the Personal Projects Analysis (PPA), a well-established methodological approach for collecting data on personal goals.[5] Personal goals are identified by the participant using his or her own phrasing, but goal dimensions are scored by standard means, allowing for comparison across participants.[5] The PPA allows for the assessment of multiple goals simultaneously, and has been used to assess personal goals among a range of populations including people with cancer and people experiencing illness.[6,9,17-19] Consistent with the PPA, at T1, we will ask participants to list up to twelve personal goals, in their own words, over the next three to four months. Participants will then be asked to choose up to six goals among the twelve that are most important to them. At T2, participants will be shown their lists of six important goals from T1 and asked to annotate any changes they wish to make. They may remove or modify existing goals, add new ones, or leave the list as is. This process will be repeated at T3 with a review of the goals identified at T2.

Personal goal dimensions

Goal dimensions are "constructs on which goals vary" (p.340).[2] We will examine both cognitive and emotional dimensions – how people think and feel about their goals. Following selection of the six most important goals at T1, participants will rate each of their six goals (scale of 0 to 10) in various dimensions consistent with the PPA (challenge, likelihood of success, autonomy, intention, attention, support, time adequacy, self-identity, hopeful, happy, sad, scared, stressed).[5,20,21] This process will be repeated at T2 and T3, following goal content review. Participants will rate any new or modified goals identified at T2 as well, but will not rate any goals removed from the list at T2. This process will be repeated at T3 with a review of the goals identified at T2.

Personal goal pursuit

Goal pursuit is defined as actions taken to strive towards goals.[2,22] At T2, participants will assess their pursuit of each of the six important goals identified at T1 (including those removed at T2) by assigning a score on a five-point scale (1 'not at all' to 5 'as much as I could') to the question, "How much did you feel you pursued this project?". At T3, participants will repeat this process for the same goals assessed at T2, along with any new goals identified at T2.

Barriers and facilitators of personal goal pursuit

Participants will identify barriers and facilitators during face-to-face interviews at T3. Questions will be open-ended, but participants will also be asked specifically about the role, if any, of Head Start aspects, cancer-related symptoms, cancer treatment, and complementary therapies as barriers or facilitators to goal pursuit.

Additional variables

At T1, we will collect demographic data on: current living situation, highest education level completed, household income, breast cancer stage, age (years, measured at HS round start date), and time since diagnosis (days, measured to Head Start round start date). At T2 and T3, we will collect data on whether participants are currently receiving medical treatment for breast cancer, and whether participants are currently receiving complementary therapy (yes/no).

Data on important Head Start program elements will be collected from exposed participants only, using the Measure Yourself Concerns and Well-Being (MYCAW) questionnaire.[23] MYCAW was developed to capture outcomes that are important to cancer patients, for use by cancer care services including complementary therapy centres. On the last day of Head Start (approximately one week before T2), the OICC will administer the MYCAW to participants. The MYCAW asks, "Reflecting on your time with the Head Start program, what were the most important aspects for you?" This data will be provided by the OICC to the investigator, with participant consent.

4.4.6 Protocol amendments

This protocol reflects amendments that were implemented after completion of the first version of the protocol (November 14, 2016), but prior to participant recruitment and data collection. Due to a delay in starting the study, we replaced an original plan to conduct feasibility testing with more intensive data collection tool development, and will recruit participants from two rounds of Head Start instead of three. Protocol amendments are presented in Chapter 5, Appendix 1.

4.4.7 Data analysis

Qualitative analyses

Barriers and facilitators to goal pursuit will be analyzed using inductive content analysis following Braun and Clarke's process guidelines.[24] Important aspects of Head Start from the MYCAW will be analyzed using the same thematic approach.

Goal content will be categorized by: (a) directional motivation (attain, maintain or avoid); and (b) by themes using directed content analysis.[25-27] Preliminary thematic categories based on life domains suggested by Little will guide analysis, but final categories will be identified in an iterative process as data is analyzed.[5]

Quantitative analysis

For the additional variables, we will calculate proportions (%) for categorical variables, and mean and standard deviation (SD), or median and range if data is non-normally distributed, for continuous variables. We will use *t*-tests and chi-square tests to compare continuous and categorical data, respectively, between study groups (if a control group is formed), with 5% significance. If there are small cell counts, we will use an appropriate non-parametric test, such as the Wilcoxon Rank Sum Test, instead.

We will calculate descriptive statistics on personal goals, each goal dimension, and goal pursuit scores (number and mean/SD or median/range, as appropriate), and on goal content (number and proportion of goals in each thematic category) within groups at each study timepoint. To analyze how personal goals change during the study, we will calculate the mean/SD (or median/range as appropriate) of the number of goals added, removed, and modified at T2 and at T3. We will use *T*-tests with 5% significance to compare the goal pursuit scores between groups (if a control group is formed).

Sub-group analyses

As this study is exploratory, we will conduct several descriptive sub-analyses to explore possible relationships with goal pursuit. We will calculate mean/SD (or median/range as appropriate) goal pursuit scores for: (a) those undergoing cancer treatment and those who are not at T2 and T3; (b) those currently receiving complementary therapy and those who are not at T2 and T3; (c) each goal content category; and (d) each goal dimension.

Missing data

The investigator will be nearby during questionnaire completion, to answer any questions that may otherwise lead to missing data. We will report the number of missing values for each variable of interest, the reasons for missing values (if known), and the number of missing data for each analysis. We will restrict quantitative analysis to individuals with complete data on variables required for a particular analysis.

Loss to follow up

Dropout may be influenced in some way by cancer (i.e. lack of time due to treatment, or lack of physical capacity due to symptoms), or be related to the exposure, as wait-list controls may feel less support to continue with the study. This study has been designed with a short timeframe to minimize loss to follow up. Non-responsive participants will be contacted twice before being considered lost to the study.

At study end, we will assess the balance of dropout rates between groups. The analysis will include data collected before participants are lost to follow up. We will report the number of participants lost to follow-up. If differential dropout occurs between T1 and T2, and there are fewer than 12 control group members with data, we will focus on analysis within the exposed

group only. If differential dropout occurs between T2 and T3, we will compare groups on goal pursuit at T2, but not at T3.

4.5 DISCUSSION

We have a unique opportunity to examine personal goals among women with breast cancer within five months of diagnosis, a critical time psychologically. Following a breast cancer diagnosis, anxiety, depressive symptoms, and emotional distress are common.[28-31] Weisman and Worden found that distress is highest two months into treatment.[29]

We anticipate that study results will contribute new knowledge about the personal goal pursuits of women with breast cancer seeking integrative oncology care, and the factors that facilitate or obstruct their goal pursuit. Recent studies suggest that people living with cancer adapt their personal goals as they adjust to treatment and survivorship, but the adaptation may be positive or negative. For example, in a 2015 study, a minority of women, following their breast cancer surgery, coped with disruptions in their personal goal pursuit by not taking any actions to overcome goal interference; this response was associated with increased perception of goal unattainability over six months.[32] People living with cancer have demonstrated use of a range of strategies to adjust their goals, including aborting a goal and engaging in a new one and aborting a goal without engaging in a new one.[9,33,34] Positive goal adjustment may have important psychological effects in a cancer context: the ability to disengage from unattainable goals and engage in different goals is positively associated with well-being.[35,36] Understanding more about goal pursuit can inform interventions aiming to support the process of positive goal adjustment.

Our study limitations include a risk of attrition bias, where wait-list controls (if used) may be more likely to drop out than Head Start participants, as discussed. People who face more barriers to goal pursuit (for example, those are heavily affected physically or emotionally by their

cancer diagnosis) may also face barriers to study participation, presenting a risk of response bias. The primary data elements will be collected via qualitative interviews and analyzed by a single unblinded researcher. To reduce the possibility of interviewer bias, an interview guide will be used. We have reviewed interview questions for possible introduction of bias. The researcher will review every interview transcript for possible introduction of bias, and adjust questions as needed to reduce bias. Other authors will also periodically review interview transcripts.

4.6 CONCLUSION

We anticipate that study findings will identify important information about the personal goals of women recently diagnosed with breast cancer. This information can inform the development of activities to support goal setting and pursuit in Head Start and other integrative oncology programs to enhance support to women recently diagnosed with breast cancer.

4.7 FIGURES AND TABLES

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Figure 1. Illustration of study procedures

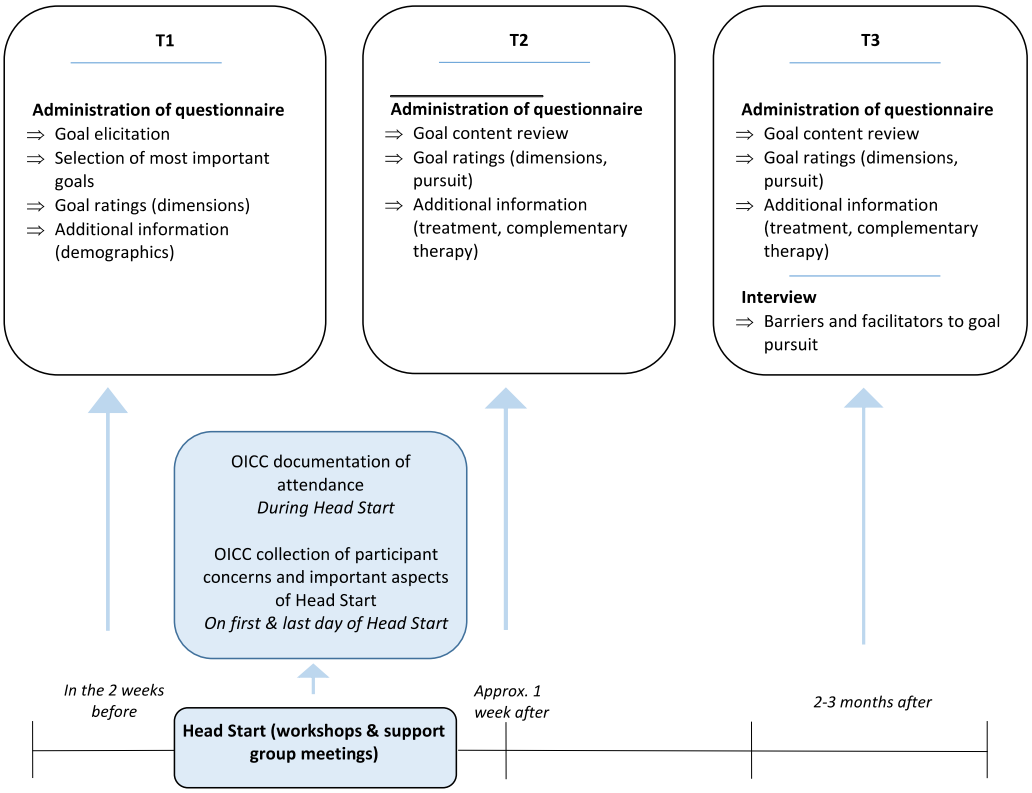

Table 1. Data sources and measurement

Variable of interest	Source of data	Method of measurement
Participation in Head Start	Head Start attendance records	Yes/no. For "yes", number of workshop days and number of support group meetings attended will be counted
Barriers and facilitators to goal pursuit, including Head Start factors, cancer-related symptoms, treatment factors, and complementary therapy factors	Participants, Head Start client records	Semi-structured, face-to-face interviews (participants); MYCAW data on important treatment aspects (Head Start client records)
Personal goal elicitation	Participants	PPA-based goal elicitation
Personal goal pursuit ratings	Participants	Ratings on a 5-point scale
Personal goal dimensions of: challenge, likelihood of success, autonomy, intention attention, support, time adequacy, self-identity, hopeful, scared, sad, happy, and stressed	Participants	PPA-based goal ratings on a 11-point scale
Demographic variables	Participants	Participant assessment. Categorical: current living situation, highest education level completed, household income (annual, Canadian dollars), breast cancer stage. Continuous: age (years), time since diagnosis (days)
Conventional cancer treatment	Participants	Participant assessment of whether treatment is currently received (y/n)
Complementary therapy	Participants	Participant assessment of whether therapy is currently received (y/n)

MYCAW: Measure Yourself Concerns and Well-Being questionnaire; PPA: Personal Projects Analysis

4.8 REFERENCES FOR CHAPTER 4

38. Ryan RM, Deci EL. Self-determination theory and the facilitation of intrinsic motivation, social development, and well-being. Am Psychol. 2000;55(1):68–78.

39. Austin JT, Vancouver JB. Goal constructs in psychology: Structure, process, and content. Psychol Bull. 1996;120(3):338–75.

40. Elliot A, Thrash T. Achievement goals and the hierarchical model of achievement motivation. Educ Psychol Rev. 2001;13(2):139–56.

41. Emmons RA. Personal strivings: An approach to personality and subjective well-being. J Pers Soc Psychol. 1986;51(5):1058–68.

42. Little BR. Personal projects: a rationale and method for investigation. Environ Behav. 1983 May 1;15(3):273–309.

43. Little B. Generative Contexts of Personal Projects Analysis. In: Little BR, Philips SD, Salmela-Aro K, editors. Personal project pursuit: goals, action, and human flourishing. Mahwah, N.J.: Lawrence Erlbaum Associations; 2007. 3-49 p.

44. Palys TS, Little BR. Perceived life satisfaction and the organization of personal project systems. J Pers Soc Psychol. 1983;44(6):1221–30.

45. Locke EA, Latham GP. Building a practically useful theory of goal setting and task motivation: A 35-year odyssey. Am Psychol. 2002;57(9):705–17.

46. Peterman A, Lecci L. Personal projects in health and illness. In: Little BR, Philips SD, Salmela-Aro K, editors. Personal project pursuit: goals, action, and human flourishing. Mahwah, N.J.: Lawrence Erlbaum Associations; 2007. 329-53 p.

47. Hullmann SE, Robb SL, Rand KL. Life goals in patients with cancer: a systematic review of the literature: Life goals in patients with cancer. Psychooncology. 2016 Apr;25(4):387–99.

48. Sulkers E, Janse M, Brinksma A et al. A longitudinal case–control study on goals in adolescents with cancer. Psychol Health. 2015 Sep 2;30(9):1075–87.

49. Stefanic N, Caputi P, Iverson DC. Investigating physical symptom burden and personal goal interference in early-stage breast cancer patients. Support Care Cancer. 2014 Mar;22(3):713–20.

50. Wanchai A, Armer JM, Stewart BR. Complementary and Alternative Medicine Use Among Women With Breast Cancer: A Systematic Review. Clin J Oncol Nurs. 2010 Aug;14(4):E45-E55.

51. Greenlee H, Balneaves LG, Carlson LE et al. Clinical practice guidelines on the use of integrative therapies as supportive care in patients treated for breast cancer. JNCI Monogr. 2014 Nov;2014(50):346–58.

52. Verhoef MJ, Mulkins A, Boon H. Integrative health care: how can we determine whether patients benefit? J Altern Complement Med. 2005 Dec;11(supplement 1):s-57 – s- 65.

53. Wallenius MA. Personal project content and stress: relations to subjective health and depressive mood. Soc Indic Res. 2007 Jan 19;81(1):35–50.

54. Little B, Gee T. The methodology of Personal Projects Analysis: four modules and a funnel. In: Little BR, Philips SD, Salmela-Aro K, editors. Personal project pursuit: goals, action, and human flourishing. Mahwah, N.J.: Lawrence Erlbaum Associations; 2007. 51–93 p.

55. Vroman K, Chamberlain K, Warner R. A Personal Projects Analysis: examining adaptation to low back pain. J Health Psychol. 2009 Jul 1;14(5):696–706.

56. Boersma SN, Maes S, Joekes K, Dusseldorp E. Goal processes in relation to goal attainment: predicting health-related quality of life in myocardial infarction patients. J Health Psychol. 2006 Dec 1;11(6):927–41.

57. Presseau J, Sniehotta FF, Francis JJ, Gebhardt WA. With a little help from my goals: Integrating intergoal facilitation with the theory of planned behaviour to predict physical activity. Br J Health Psychol. 2010 Nov;15(4):905–19.

58. Presseau J, Boyd E, Francis JJ, Sniehotta FF. Goal conflict and goal facilitation in community-based cardiac rehabilitation: A theory-based interview study. Psychol Health Med. 2015 Feb 17;20(2):227–38.

59. Gollwitzer PM, Brandstätter V. Implementation Intentions and Effective Goal Pursuit. J Pers Soc Psychol. 1997;73(1):186–99.

60. Paterson C, Thomas K, Manasse A, Cooke H, Peace G. Measure Yourself Concerns and Wellbeing (MYCaW): An individualised questionnaire for evaluating outcome in cancer support care that includes complementary therapies. Complement Ther Med. 2007 Mar;15(1):38–45.

61. Braun V, Clarke V. Using thematic analysis in psychology. Qual Res Psychol. 2006 Jan;3(2):77–101.

62. Elliot A, Friedman R. Approach-avoidance: a central characteristic of personal goals. In: Little BR, Philips SD, Salmela-Aro K, editors. Personal project pursuit: goals, action, and human flourishing. Mahwah, N.J.: Lawrence Erlbaum Associations; 2007. 97–118 p.

63. Wiese B. Successful Pursuit of Personal Goals and Subjective Well-Being. In: Little BR, Philips SD, Salmela-Aro K, editors. Personal project pursuit: goals, action, and human flourishing. Mahwah, N.J.: Lawrence Erlbaum Associations; 2007. 301–25 p.

64. Hsieh H-F, Shannon SE. Three Approaches to Qualitative Content Analysis. Qual Health Res. 2005 Nov;15(9):1277–88.

65. Stanton AL, Wiley JF, Krull JL et al. Depressive episodes, symptoms, and trajectories in women recently diagnosed with breast cancer. Breast Cancer Res Treat. 2015 Nov;154(1):105–15.

66. Weisman AD, Worden JW. The existential plight in cancer: significance of the first 100 days. Psychiatry Med. 1976;7(1):1–15.

67. Zabora J, Brintzenhofeszoc K, Curbow B, Hooker C, Piantadosi S. The prevalence of psychological distress by cancer site. Psychooncology. 2001;10(1):19–28.

68. Henselmans I, Fleer J, de Vries J, Baas PC, Sanderman R, Ranchor AV. The adaptive effect of personal control when facing breast cancer: Cognitive and behavioural mediators. Psychol Health. 2010 Nov;25(9):1023–40.

69. Stefanic N, Caputi P, Lane L, Iverson DC. Exploring the nature of situational goal-based coping in early-stage breast cancer patients: a contextual approach. Eur J Oncol Nurs. 2015;19:604-11.

70. Pinquart M, Fröhlich C, Silbereisen RK. Testing models of change in life goals after a cancer diagnosis. J Loss Trauma. 2008 Jun 27;13(4):330–51.

71. Janse M, Fleer J, Smink A, Sprangers MAG, Ranchor AV. Which goal adjustment strategies do cancer patients use? A longitudinal study. Psychooncology. 2016 Mar;25(3):332–8.

72. Wrosch C, Scheier MF, Miller GE, Schulz R, Carver CS. Adaptive self-regulation of unattainable goals: goal disengagement, goal reengagement, and subjective well-being. Pers Soc Psychol Bull. 2003 Dec 1;29(12):1494–508.

73. Schroevers M, Kraaij V, Garnefski N. How do cancer patients manage unattainable personal goals and regulate their emotions? Br J Health Psychol. 2008 Sep;13(3):551–62.

CHAPTER 5: Personal goals among women recently diagnosed with breast cancer and participating in an integrative oncology educational program: a mixed-methods cohort study (Manuscript #4)

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5.1 PREFACE

This manuscript has not yet been submitted for publication.

5.2 PROLOGUE TO CHAPTER 5

The expected sample size was 18 to 36 participants, as outlined in the protocol for this study (Chapter 4). This was based on expected enrollment in the Head Start program (12 participants per round, plus a waiting list of up to 12 women). Enrollment in Head Start was a factor out of my control. Fifteen women were enrolled in the two iterations of Head Start during which I conducted this study, thus forming a smaller pool of potential recruits into the study. In addition, though we had planned for study recruitment to take place up to two weeks before each Head Start round began, many participants enrolled only a few days before, and were invited to participate in the study with just a few days' notice. This may not have been enough time for women who might have felt overwhelmed by having new commitments. In the end, eight of the potential women enrolled in my study.

The study protocol (see Chapter 4) outlined a plan to include a control group of women on a waiting list to join Head Start, if the following criteria could be met: program demand exceeded the OICC's maximum of 12 women per iteration and a minimum of 12 wait-list controls could be enrolled. These criteria were not met during enrollment. Therefore, the completed study was a single cohort, prospective study, conducted with participants in Head Start.

The inclusion of wait-list controls would have enabled a comparative qualitative and quantitative analysis of the personal goal pursuit, barriers and enablers to goal pursuit, and goal content of women participating in Head Start against those who wanted to participate but were unable to. A control group would have allowed a more robust evaluation of the effects of Head Start, a program that does not have a personal goal-setting component but that is designed to help

women access resources for improved coping and well-being in the months following breast cancer diagnosis. Due to the lack of a control group, planned between-group inferential statistics could not be performed and analysis was restricted to within-group description.

We changed the description of primary and secondary outcomes and analyses in the study protocol to qualitative and quantitative outcomes and analyses in the final study report.

5.3 ABSTRACT

Background: Personal goal-setting and their pursuit are associated with well-being. Women recently diagnosed with cancer may experience both decreases in well-being and in their ability to pursue their personal goals. Understanding what their personal goals are and the barriers and enablers of their personal goal pursuit is an important aspect to providing supportive, patient-centred care to women recently diagnosed with breast cancer. This study aimed to identify the personal goals of a cohort of women with breast cancer, to describe the characteristics of their personal goals over four months, and to identify barriers and enablers to their pursuit.

Methods: In this mixed-methods cohort study, we recruited women participating in an integrative oncology psychoeducational program in Ottawa, Canada. On a baseline questionnaire, participants identified their personal goals and rated them on various dimensions. On two follow-up questionnaires at one and three months, participants re-assessed their goals and their goal pursuit. In an interview at three months, they identified barriers and facilitators to the pursuit of their goals. We analyzed quantitative data using descriptive statistics and qualitative data using thematic content analysis.

Results: Of fifteen women invited to participate, eight enrolled and six completed the study. Health, psychological, social, and leisure goals were commonly identified by participants, and most women set "approach" goals. At all time points, participants rated their goals highly on the dimensions of likelihood of success, autonomy, intention, support, self-identity, attention, time adequacy, hopeful, and happy and gave moderate to low ratings for the goal dimensions of being challenging, and feeling scared, sad, and stressed. Women reported being moderately successful at pursuing their important goals, and were generally more successful if they did not make any changes to the goals set at baseline. Enablers and barriers to goal pursuit were identified.

Conclusion: This study identified important information about the personal goals of women recently diagnosed with breast cancer that can help to support the process of positive goal adjustment and enhance support to these women.

5.4 INTRODUCTION

Everyday life is characterized by the pursuit of multiple personal goals, such as seeking a promotion at work or exercising daily, which together describe important expressions of life motivations.[1] A *personal goal* is an individual's cognitive expression of a desired state or process that provides directional motivation towards that state; it defines what individuals do and strive for in everyday life[2,3] and can be expressions of targets or motivations that are important to an individual. Goals may be described at various levels of aggregation such as higher order goals (e.g. life satisfaction) or mid-level or lower-order goals.[2] Mid-level goals often become the inputs of higher-order goals and life meaning.[2,4] Cycling to work facilitates the higher-order goal of being a physically active person. *Personal projects* are a mid-level goal concept, individually defined, characterized by action and shaped by an individual's environment.[5-7] For consistency, we use the term *personal goals* in the sense of personal projects. Goal-setting theory suggests that conscious goal setting and motivation are important in determining individual performance and satisfaction.[8] In the general population, successful goal pursuit (goal progress) is positively associated with well-being.[1,4,9-14] The Selection, Optimization, Compensation (SOC) theory of human development posits that the likelihood of setting, pursuing and attaining our personal goals is affected by age, capabilities, the resources we have to act on those goal, and individual processes of using available resources. In the SOC framework, the setting and pursuit of personal goals are influenced by the resources an individual can commit to such activity.[15,16] Resource

losses, such as the time and energy lost during a significant illness such as cancer, prompt compensation, the act of choosing and using different means to attain one's goals.[17]

Diagnosis with a serious illness such as cancer can affect an individual's day-to-day physical resources and time, thus disrupting the pursuit of their personal goals.[18-20] Among women with breast cancer, a higher burden of physical symptoms has been associated with a reduced ability to pursue goals, and higher psychological distress.[21] Reducing physical symptoms or distress are common reasons that women with breast cancer seek complementary therapy.[22] The past decade has seen the emergence of an approach known as integrative oncology, which integrates evidence-based complementary therapies and medical treatment and emphasizes patient-centered care and coordination between providers.[23] The Ottawa Integrative Cancer Centre (OICC) is a non-profit organization that works with people with cancer, their families, and their health care providers to develop and provide complementary therapy and care to support conventional treatment. The OICC is engaged in research and is at the forefront in the development of integrative oncology delivery and evaluation in Canada.[24] With community support, the OICC developed and operates the Head Start program, to address the distress expressed by many of their clients recently diagnosed with breast cancer. Initially funded by a singer-songwriter group called Babes4Breasts, Head Start is free of charge to participants and offers education, resources, and skills to improve women's knowledge of integrative care options, reduce fear and anxiety, and strengthen their ability to cope with their diagnosis and incorporate life changes associated with living well with cancer.

Personal goals are important to measure and understand in patient-centred interventions designed to support women's coping and improved well-being. Specifically, an understanding of the factors that hinder or enable women recently diagnosed with breast cancer to pursue their personal goals would inform the development of effective goal-setting and pursuit interventions

for this population. Few studies have examined personal goal pursuit or the content of women's personal goals following a cancer diagnosis. Our scoping review of studies examining personal goal-setting among women with breast cancer found that women's personal goals shortly after a diagnosis of breast cancer have not been evaluated in the literature. In another study, participants in an integrative oncology program in Vancouver, Canada were asked to identify personal goals related to their participation, goals that highlighted important motivations related to cancer: improved well-being, increased chance of remission, increased physical energy, more effective pain management, and a return to active living.[25]

In partnership with the OICC, we examined the personal goals of women participating in the Head Start program. Our primary objective was to identify the perceived barriers to and enablers of personal goal pursuit, including those related to Head Start. The secondary objectives were to describe the characteristics of participants' personal goals (goal content and specific dimensions describing views about their goals) over time, and to analyze whether women pursue their most important goals. *Goal dimensions* are factors that express how women think or feel about their goals (e.g. difficulty, control).[2] They can be associated with important outcomes: higher goal importance may be associated with better psychological outcomes among people living with cancer, and higher goal stress with worse depressive mood and worse subjective health.[18,26] Towards their program objectives, Head Start enables women to work on aspects of mindfulness, awareness of emotions, identifying social supports and use of coping mechanisms. Based on the aims and activities of Head Start, we hypothesized that there would be an increase in ratings of self-identity, perceived autonomy, and perceived support from others over time.

5.5 METHODS

We developed and conducted the study according to our published protocol.[27] From the original protocol, one major amendment was made to accommodate emerging time constraints: We recruited and collected data from participants of two iterations of Head Start instead of our planned three iterations. A full list of amendments and their reasons is presented in Appendix 1. We used the STROBE checklist for cohort studies to guide our reporting.[28]

We conducted a mixed-methods cohort study at the OICC in Ottawa, Ontario, Canada. To be eligible, participants needed to be enrolled in one of two pre-identified iterations of Head Start in 2017, be aged 18 years or older, be female, have sufficient English comprehension, and have received a breast cancer diagnosis no more than five months prior to the start of the Head Start iteration for which they were enrolled. Their recent breast cancer diagnosis must have been their first cancer diagnosis. Participants who were unable to provide informed consent were excluded. Inclusion criteria were similar to the OICC's eligibility criteria for Head Start participation. The Ottawa Health Science Network Research Ethics Board and the Canadian College of Naturopathic Medicine Research Ethics Board approved the study protocol and procedures.

5.5.1 Study procedures

Participant identification and enrollment

Participants were recruited at the OICC. Following OICC standard procedure, a Care Coordinator telephoned or met in person with potential participants to determine eligibility for Head Start prior to program initiation. If eligible and not already enrolled, the individual was asked to enroll online. In the two weeks prior to Head Start, the Coordinator either called or e-mailed Head Start participants to inform them of the study (the recruitment script is presented in Appendix 2; the letter of information is presented in Appendix 3). The participant was asked to

contact the researcher (AC) directly if interested in participating. The researcher arranged a one-on-one, face-to-face meeting with interested women to review the consent form, obtain written consent, and enroll the participant. Verbal consent to continue with the study was sought at the beginning of each subsequent meeting.

Data collection

We collected qualitative data concerning barriers and enablers to goal pursuit and goal content through one-on-one, face-to-face interviews and quantitative data concerning goal pursuit and goal dimensions with paper-based questionnaires. A topic guide was developed to guide discussion during interviews. We collected data at three time points during each Head Start iteration: (T1: baseline) Zero to five days before the first day of Head Start; (T2) One to seven weeks after Head Start ended; and (T3) Two-and-a-half to four months after Head Start ended. Head Start was conducted over five weeks. T1 was scheduled to take place immediately following consent if time did not permit two separate meetings (i.e. between consent and start of Head Start). The data collection process is shown in Figure 1. All data were collected either at the OICC or at a quiet location amenable to both the participant and AC. Participants were offered reimbursement for any required taxi fares or parking costs.

All interviews were audio-recorded with permission from participants and transcribed by AC. JP provided feedback on several transcripts used by AC and refined as needed after each interview.

Development of data collection tools

In developing the data collection tools, we elicited feedback from colleagues with expertise in relevant areas. Two women over the age of 50 completed the T1 and T2 questionnaires to assess comprehension, suitability, and clarity while the interview guide was piloted with female

acquaintances of AC. A full description of data collection tool development is presented in Appendix 4. Data collection tools are presented in Appendix 5.

5.5.2 Variables

A summary of data sources and methods of assessments is presented in Table 1. *Participation in Head Start* was measured by count of the number of workshop days attended (0, 1, or 2) and number of weekly support group meeting attended (0 to 4), as documented in the OICC's attendance records and linked to study records.

5.5.3 Outcome data measurement

Demographic and clinical variables

Demographic variables captured included current living situation, highest education level completed, household income, and age. Clinical variables captured include breast cancer stage, time since diagnosis, current state of conventional cancer treatment and current complementary therapy received by the participant. All variables were self-reported and measured categorically except for age (continuous, years) and time since diagnosis (continuous, days). We collected data on demographic variables, breast cancer stage, and time since diagnosis on the T1 questionnaire. On the T2 and T3 questionnaires, we collected data on current receipt of conventional cancer treatment and of complementary therapy.

Personal goal elicitation

Data related to personal goals were collected using Personal Projects Analysis.[5] Personal Projects Analysis is idiographic: goals are identified by the participant using his or her own phrasing. It is also nomothetic: goals can be rated using Likert-type scales along a range of dimensions (e.g. importance), allowing for comparison across participants.[5] It allows for the assessment of multiple goals held simultaneously.[7] Personal Projects Analysis has been used to

assess goal pursuit among people with cancer[19] and people experiencing illness.[29,30] At T1, participants were asked to list up to twelve personal goals, in their own words. *Personal goals* were defined as those that they planned to pursue in their daily lives over the next three to four months. Participants were then asked to choose up to six goals from that list that were most important to them ("most important personal goals").

Goal content review

At T2, participants were shown their lists of up to six of their most important personal goals stated at T1. They were asked to assess whether the list reflected their current most important goals for the next two to three months. They could remove or modify existing goals, add new ones, or leave the list as is. This process was repeated at T3 with a review of the goals identified at T2. Definitions of added and modified goals are presented in Appendix 5.

Personal goal rating

Personal goal dimensions are characteristics of goals that differ from goal to goal.[2] Ratings on goal dimensions were assessed at T1 using a modified version of Personal Projects Analysis and following selection of the six most important goals. Participants rated each of their six important goals (scale of 0 to 10) along key dimensions consistent with Personal Projects Analysis.[5,31,32] Dimensions rated in this study were: challenge, likelihood of success, autonomy, intention, attention, support, time adequacy, self-identity, hopeful, scared, sad, happy, and stressed. This process was repeated at T2 and T3 with the list of six important goals identified at those time points.

The goal dimensions comprised both cognitive and emotional assessments: how people thought and felt about their goals. Personal Projects Analysis methods are described to encompass up to 27 standard dimensions to select from to suit the study research questions.[33] To minimize

participant response burden in this clinical population, we selected a subset of key dimensions on which women were asked to rate their goals. Our dimension selection was guided by the Selection, Optimization and Compensation theory applied to goal setting and goal pursuit,[15,16] and by input from AP and JP on dimensions most relevant to the study population. Eleven of the 13 dimensions that we measured were standard Personal Projects Analysis dimensions; attention and intention were added by the authors as important aspects of Selection, Optimization and Compensation theory. Adapted from Personal Projects Analysis, we included questions that defined each dimension and provided participants with guidance for rating each dimension (e.g. "How much do you intend to pursue this project, that is, how much do you want to pursue this project? Use 10 if you fully intend to pursue the project, and 0 if you do not intend to pursue it at all.") Questions for each dimension are presented in Appendix 6.

Personal goal pursuit rating

Goal pursuit was defined as the actions taken to strive towards goals. At T2, participants assessed their pursuit of each of the six most important goals identified at T1, even if a goal was removed at T2. Participants were asked to assign a score on a five-point scale (1 'not at all' to 5 'as fully as I could') to the question, "How much did you feel you pursued this goal over the past thirty days?". At T3, participants were asked to assess their pursuit of these same goals and of any new goals identified at T2 "over the past [2-3] months". If goals were modified at T2, the modified wording was used in the assessment at T3.

Barriers and enablers to goal pursuit

Data on barriers and enablers were collected from interviews with participants at T3, immediately following completion of the questionnaire. Barriers were defined as the physical, psychological, and other self-perceived internal and external obstacles that hinder participants in

pursuing their goals. Enablers were defined as the physical, psychological, and other self-perceived internal and external supports that assist participants in pursuing their goals. Each participant was asked to select the goal that she had pursued the most and the one she had pursued the least (the goals with the highest and lowest pursuit score at T3, respectively). If multiple goals had the same score, the participant was asked to select the goal most important to her. Questions about barriers and enablers were open-ended. If not identified by participants, we planned to ask about the influence of four factors relevant to the population on their goal pursuit: breast cancer-related symptoms, treatment-related effects, Head Start participation, and use of complementary therapy.

5.5.4 Variable transformations

The *date of breast cancer diagnosis* was transformed into the variable *time since breast cancer diagnosis*. One participant provided only the month of diagnosis. For analysis, we calculated the maximum time since diagnosis (from the first date of that month) and used that date to calculate the study median.

5.5.5 Sample size

This study was purposively exploratory and descriptive; because no effect sizes were sought, a sample size calculation was not applied. We sought to enroll as many women as possible within a defined period. We planned to interview all women even if data saturation was reached in order to identify as many barriers and enablers as possible. The sample size depended on the number of women interested in participating in the planned Head Start iterations (to a program maximum of 12 women per iteration).

5.5.6 Planned analyses

The analysis was largely descriptive given the study purposes, design, and obtained sample size. Descriptive statistics (proportions for dichotomous and categorical variables and median and ranges for continuous variables) were calculated for demographic and clinical variables. Because this study aims to understand differences among women more than differences among goals and a multi-level analysis was beyond the scope of this study, we selected the participant as the unit of analysis. In order to focus the analysis at the participant level rather than the goal level, a sample-specific median was calculated for quantitatively scored, goal-related variables, such as goal content categorization, goal dimensions, and goal pursuit ratings.[31,33,34] For each variable, we first calculated a participant-specific median of ratings across all of their goals for each participant. Then we calculated a sample-specific median across the participant-specific medians. For example, for participant 1, we calculated the median of her six 'goal challenge' ratings for her six personal goals at T1 (her participant-specific median), then repeated the process for each participant. We then calculated the sample-specific median across all eight participant-specific medians to find the T1 sample-specific median rating for 'goal challenge'. Thus for the dimension of 'goal challenge', the sample-specific median at T1, T2, and T3 provided a capacity to descriptively assess variation over time in how challenging participants felt about their set of most important goals as a whole, rather than how challenging an individual goal was over time.

Qualitative analyses

Goal content was categorized in two different ways: by directional motivation (attain, maintain or avoid);[9,35] and by an initial set of pre-defined themes using directed content analysis.[36] Preliminary thematic categories were based on life domains (health-related, psychological, social, achievement, and leisure) as defined and used by Pinquart and colleagues on a study of the life

goals of cancer patients.[17] During data analysis, we created one additional category, *other*, for goals that did not fit with the pre-identified categories, and sub-themes for each theme in an iterative process. All goals were coded for their primary affiliation only. Experts familiar with the issues faced by women recently diagnosed with breast cancer (DS, AP, and SY) provided guidance on coding decisions. *Barriers and enablers of goal pursuit* were analyzed using inductive content analysis.[36] Analysis followed Braun and Clarke's process guidelines[36] which includes: (1) familiarizing oneself with the data; (2) generating initial codes; (3) searching for themes; (4) reviewing themes; (5) defining and naming the themes; and (6) producing the report. Our process for the first five steps was as follows: (1) transcribe the data, verify the transcription and read the transcript multiple times; (2) identify and code all barriers and enablers of goals discussed; (3) identify potential groupings (themes) and sub-themes of the coded data on barriers and enablers; (4) review themes to ensure that they were meaningful and distinct; and (5) create definitions for each theme and sort the data into the final themes. This process was conducted iteratively until appropriate themes that reflected the data were identified. AC conducted all steps, with review of potential themes and sub-themes by JP, DF and DS. We systematically distinguished between *new* and *modified goals* added at a follow-up point. Modified goals incorporated minor changes (e.g. the frequency, timing or location of a goal) to a previously identified goal, whereas new or added goals represented a major change from an existing goal (e.g. change in the goal content category or goal target).

Quantitative analyses

The primary unit of analysis was the participant, as we were interested in understanding differences in goal characteristics and changes across participants. The study population was small (<10), so we calculated medians and ranges for the number of goals at T1, T2, and T3, for each

dimension rating at T1, T2, and T3, for goal pursuit scores at T2 and T3, and for the number of goals added, removed, or modified at T2 and T3. Descriptive statistics on goal content (the number and proportion of goals in each category at T1, T2, and T3) were calculated.

Additional analyses

Because this study was exploratory in nature, an additional descriptive analysis was conducted to explore possible relationships with goal pursuit: the median and range of goal pursuit scores were calculated for each goal content thematic category. During data analysis, we decided to conduct a post-hoc analysis of characteristics of and goal pursuit scores for goals added, removed, or modified during the study and for the number of major changes to goal lists (goals added and removed), as the lengths of time available to pursue these goals were shorter than for goals identified at T1. We defined a *major goal change* as the removal of a goal with or without the addition of a new goal and a *minor goal change* as the modification of an existing goal.

Missing data

This study mitigated the possibility of missing data by providing a brief, verbal, scripted introduction to each questionnaire before asking the participant to complete it. The primary researcher (AC) remained nearby (but outside the room) during questionnaire completion to answer any questions that arose. Quantitative analysis was restricted to individuals with complete data on variables required for a particular analysis.

Loss to follow up

This study was designed with a short timeframe to minimize loss to follow up. Data collected from participants before they were lost to follow up were included in the analysis as appropriate.

5.6 RESULTS

5.6.1 Participants

Fifteen women enrolled in Head Start were invited to participate in this study. Eight met eligibility, provided informed consent, and enrolled. The remaining women did not respond (n=3), declined to participate (n=3) or did not meet eligibility (n=1). Maximum enrollment in Head Start was not reached during either iteration, thus no waiting list was formed and no woman was approached to enroll as a control group member. This study consisted of a single cohort comprising women that participated in Head Start. Study enrollment and drop out are detailed in Figure 2. At baseline, the median age of participants was 50 years, and the median time since breast cancer diagnosis was 75 days. Participant characteristics are summarized in Table 2. Participants completed the T1 questionnaire in approximately half an hour (median 23.5 minutes, range 12 – 31). On average, it took participants just under 15 minutes to complete the remaining questionnaires (T2: median 14.5, range 9 – 19; T3: median 14, range 4 – 21). The median interview length was 53 minutes (range 23 – 72).

5.6.2 Number of goals and goal changes over the study

At T1 (0 – 5 days before Head Start commencement), eight participants identified a median of 12 personal goals (range 6 – 12). Each participant selected six goals that were most important to them. Over the remainder of the study, the six participants with complete follow-up retained the majority of the important goals they selected at T1. At T2, each participant identified six important goals. Two women made no major changes to their lists of important goals, three women made one major change (each removing and adding one goal), and one woman made two major changes (removing and adding two goals). At T3, the six participants identified a median of six important goals (range 1 – 6). At T3, two women made no major changes to their lists of

important goals, two women made one major change (one removing and adding a goal, one removing a goal without adding a new one), one woman made two major changes (removed two goals and replaced both with new goals), and one woman removed five goals without adding any new ones. Three women modified four goals at T2 and one woman modified one goal at T3. All goals modified at T2 were removed at T3.

5.6.3 Content of participants' personal goals

Among the personal goals identified at T1, participants each identified a median of three psychological goals, 2.5 social goals, 2.5 health goals, 1 leisure goal, 0.5 achievement goals and 0 goals related to what we have called "ordering one's affairs", legal and financial. Seven women each identified at least one psychological, one health and one social goal. Six women identified at least one leisure goal, four identified at least one achievement goal, and three identified at least one ordering one's affairs goal. Looking at the directionality of described goal pursuit, women each identified a median of ten approach goals, one avoidance goal, and one maintenance goal.

Among the most important goals selected at T1, participants each identified a median of two psychological goals, two health goals, and one social goal; and a median of five approach goals, one maintenance goal, and no avoidance goals. At T2 and T3, participants had a median of two psychological goals, one health goal, one social goal, and zero goals in the remaining thematic categories. They had a median of five approach goals, one maintenance goal and no avoidance goals at both timepoints. Characteristics of participants' personal and important goals, goal changes, and goal pursuit scores are summarized in Figure 3. Descriptive statistics of participants' personal and important goals and goal content are presented in Tables 3 and 4, and visualizations of goals by thematic area are presented in Figures 4a – 4f.

5.6.4 Goal dimensions

At all three time points, participants rated their goals highly on the dimensions of likelihood of success, autonomy, intention, support, self-identity, attention, time adequacy, hopeful, and happy (sample-specific medians ≥ 7.25 on a scale of 0 to 10), and gave moderate to low ratings for the goal dimensions of being challenging, and feeling scared, sad, and stressed (sample-specific medians ≤ 5.50). The scores for challenge, attention, support, intention, feeling hopeful, and self-identity increased from T1 to T2 and increased or remained the same from T2 to T3. The sample-specific medians for likelihood of success, time adequacy, and feeling happy increased from T1 to T2 and decreased from T2 to T3. Sample-specific medians for autonomy, feeling scared and feeling sad remained the same for all three timepoints. Feelings of stress decreased from T1 to T2 and increased from T2 to T3. General trajectories of change remained the same when dropouts were excluded from analysis except for "scared" which decreased from T1 to T2 and remained the same from T2 to T3 (*data not shown).* Sample-specific medians for each dimension are presented in Table 4 and Figure 5.

5.6.5 Goal pursuit

Across participants, the sample-specific pursuit median at T2 for important goals identified at T1 was 3.25 (range 2.50 to 5.00). At T3, the sample-specific pursuit median for important goals identified at T1 and T2 was 3.50 (range 1.00 to 5.00). Descriptive statistics for participants' personal goal pursuit are presented in Table 5 and Figure 6. In post-hoc exploratory analyses, we found that four women removed goals at T2 with a sample-specific pursuit median for those goals of 3.0 (range 2.0 – 4.0). At T3, four women removed goals, with a sample-specific pursuit median for those goals of 5.0 (range 1.0 – 5.0). Four women added goals at T2, with a sample-specific pursuit median of 2.25 (range 1.0 – 3.0) for those goals at T3. Three women modified goals at T2

and at T3, with a sample-specific pursuit median of 3.0 at T2 (range 2.5 – 5.0) and 4.0 at T3 (range 1.0 – 5.0). Dimension scores for the goal changes are presented in Table 6.

The two women who made more than two major changes to their list of goals at T2 and T3 had participant-specific pursuit median of 2.0 and 3.0 at T2 and 1.0 and 3.0 at T3. The three women who made one to two major changes had participant-specific pursuit medians ranging from 3.0 to 4.5 at T2 and at T3. At both follow-ups combined, one woman made no changes to her list of important goals and had a participant-specific pursuit median of 5.0 at T2 and T3.

5.6.6 Barriers to goal pursuit

All six participants discussed barriers and enablers to the pursuit of their most successfully pursued goal. Five of six discussed the barriers and enablers to the pursuit of their least pursued goal; one participant asked to end her interview before discussion of that goal.

We identified five types of barriers to goal pursuit that women identified during their interviews: the experience of breast cancer treatment; fear; a goal being more challenging than expected; lack of alignment with self-identity or values; and goal interference. Example quotes for each barrier are presented in Table 7. Definitions of these themes and a longer list of quotes that contribute to each theme appear in Appendix 7. We did not ask all participants about the impact of cancer-related symptoms or treatment as planned.

i. The experience of breast cancer treatment

Undergoing breast cancer treatment was mentioned most often by participants as a barrier to goal pursuit; the experience of living with breast cancer and/or undergoing breast cancer treatment reduced participants' resources (physical, tangible, emotional) available for goal pursuit. Breast cancer treatment affected participants in three main ways: a) *physical side effects* (feelings of illness and lack of energy following treatment); b) high number of *medical appointments*

disrupted daily routines; and c) *emotional or psychological effects* (emotional or mental fatigue that followed adverse outcomes or experiences with treatment). These three experiences hindered their ability, time, and energy to pursue their goals. All but one woman (n=5) identified treatment as a barrier without prompting, and one woman was not asked due to time constraints. Three women discussed breast cancer symptoms (physical side effects) without prompting, one was asked directly, and two were not asked due to time constraints.

ii. Fear

A feeling of fear while pursuing a goal, or fear of the consequences or outcomes of goal pursuit, presented as a barrier for three participants. Participants specifically mentioned fear of not being physically strong enough to pursue a goal, fear of being alone, and fear of facing mortality.

iii. Being more challenging than expected

Five participants found their goal to be more challenging than expected. These challenges related to either the process of goal pursuit or inputs required to pursue a goal, such as challenge in finding adequate social support, having to deal with challenging or stressful social situations, and having adequate time or favourable external conditions (specifically, weather).

iv. Lack of alignment with self-identity or values

Three participants shared thoughts, feelings or beliefs that pursuing the goal did not align fully with their individual identities or values. A few women talked about the difficulty in shifting from their normal practices of taking care of others to focus on oneself and one's own goals. For example, one woman talked about how her goal to interact a certain way with other people was different from the way she had interacted with people before her breast cancer diagnosis.

v. Goal interference / competing priorities

Three women identified the pursuit of other activities, goals or responsibilities outside of treatment requirements as barriers to pursuing the goals discussed in interviews. A common sub-theme was the responsibility that some women felt to care for parents or children, to help with the practicalities of their lives such as accompanying them to medical appointments or providing basic necessities. For some, the priority was taking care of oneself mentally and physically, getting enough rest or focusing on self-care, rather than pursuing the goal. One participant needed to be accompanied by another adult to pursue her goal but found that her partner was not available to provide that support because somebody needed to stay home with their children.

5.6.7 Enablers of goal pursuit

We identified ten types of enablers of goal pursuit: social supports; prioritization of the goal; the experience of living with breast cancer and through treatment; changing definitions of goal progress during goal pursuit; identifying and utilizing helpful resources; having time; goal facilitation; changing one's thinking; Head Start; and complementary therapies. Our definitions of these enabler types are described in Appendix 7. We did not ask all participants about the impact of Head Start participation or complementary therapies as planned.

i. Social supports

All of the women interviewed (n=6) identified social supports as enablers of their goal pursuit. Support came from a wide range of people: partners, other family members, friends, work colleagues, medical care providers, and communities. Sometimes social support was provided without request from the participant, and sometimes it was sought out. Social supporters provided

emotional and tangible support for goal pursuit. Two women mentioned that their social supports reduced their social or familial responsibilities, which helped them focus on goal pursuit.

ii. Prioritization of the goal

Another common enabler mentioned by five women was the individual's conscious efforts to dedicate time and energy to pursuing a goal, and the articulation of a particular goal as a priority. One woman, however, came to feel the opposite about her highly pursued goal, that it was simply not a priority and that this mitigation of the goal's importance made it easier for her to attain.

iii. The experience of living with breast cancer and through treatment

Although several women identified breast cancer treatment as a barrier to goal pursuit, aspects of living with breast cancer were also identified as enablers of goal pursuit. For four women, motivation for a successful recovery or better health in the future enabled their goal pursuit. One woman mentioned that feeling better after treatment helped her to eventually begin pursuing her less pursued goal, and one woman identified an opportunity for personal growth and learning from her experience with cancer that enabled her goal pursuit.

iv. Changing definition of progress during goal pursuit

Another enabler was a shift in how three participants defined or measured goal progress between the time they set their goals and the interview. That change was conscious for some and unconscious for others. Generally, the changes were to a more expansive definition of their goals or related concepts, such as the aspects of "life" that were important in pursuing "work-life balance."

v. Identifying and utilizing helpful resources

Being able to identify and put into place things, people or strategies helped three women in their goal pursuit. Women provided concrete examples of physical or abstract resources, including obtaining appropriate clothing and getting into routines.

vi. Having time

Having time, whether the women actively sought it or were given it, was also a goal pursuit enabler for two women. Having more time than usual was often identified as a function of having extended time away from work due to their breast cancer treatment.

vii. Goal facilitation

Two women identified the pursuit of other goals within their goal systems as enablers of the goals discussed in interviews. The successfully pursued goals were psychological, and the "enabler" goals had been identified by each woman in her list of important goals in the study.

viii. Changing one's thinking

One participant spoke specifically about how changing her thinking helped her pursue her goal. She spoke about feeling that she had lost control of her life, and that shifting her focus to the things that were within her control enabled her goal pursuit.

ix. Head Start

All but one woman (n=5) were asked specifically if any aspect of participating in the OICC's Head Start program had enabled her goal pursuit. Four women felt that it had in one of three broad ways. One way was by having helpful or positive practices emphasized, such as meditation. Another was by learning new skills or techniques for those practices, such as visualization or breathing exercises. A final way was by developing a sense of camaraderie

through the small group format, and listening to the advice of others, both enablers and peers. Two women were unsure if the program enabled their goal pursuit or felt that it did not.

x. Complementary therapy

All of the participants indicated receiving complementary therapy at T2 or T3, or both. Four women were also asked directly if receiving complementary therapies had enabled their goal pursuit. Three women indicated that they were receiving complementary therapy (e.g. massage therapy, acupuncture, naturopathic medicine) and felt that this had helped their goal pursuit.

5.6.8 Sub-analyses

At T2 and T3, goal pursuit scores were highest for health goals (T2 median 4.0, range 2.0 – 5.0; T3 median 4.0, range 1.5 – 4.5), and lowest for "ordering one's affairs" goals (one participant: T2 median 1.5; T3 median 2.0). The medians for psychological, social, leisure, and achievement goals at both T2 and T3 ranged from 3.25 to 3.75. Goal pursuit scores by thematic area are presented in Figure 6.

5.6.9 Additional analyses

We did not conduct planned analyses for those undergoing breast cancer treatment compared to those who were not, or for those receiving complementary therapy compared to those who were not. All participants at T2 were undergoing breast cancer treatment and receiving complementary therapy and all but one were undergoing treatment and receiving therapy at T3.

5.7 DISCUSSION

5.7.1 Summary of main findings

Women with breast cancer taking part in an integrative oncology education program were able to articulate several personally important personal goals that were related to health, psychology, social lives, leisure, achievement, and putting affairs in order. The extent of their goal pursuit varied across goals and participants, and women encountered several different types of barriers and enablers that hindered or helped their goal pursuit, respectively. To our knowledge, our study is the first to publish data either about the barriers and enablers of goal pursuit or the many dimensions of the personal goals of women recently diagnosed with breast cancer.

5.7.2 Content of women's personal goals

We anticipated that distress associated with a recent breast cancer diagnosis may make it difficult for some women to identify personal goals. Most women, however, identified the maximum number of goals at each time point, even though they had the option of not listing any personal goals. Our study found that the thematic categorization of women's personal goals into life domains mostly aligned with categories used in a previous study with people with cancer, with only four goals that we categorized as "ordering one's affairs".[17] Our study found greater emphasis among participants on psychological, health and social goals and lesser emphasis on achievement, leisure and "ordering one's affairs" goals. This is somewhat consistent with previous studies. One study using the same categorizations as our study found that people with cancer have more health-related goals and fewer achievement and leisure goals than healthy people; another study found that a high prevalence of health-related goals among women with breast cancer.[17,19,38] Other studies have found leisure and social goals to be more common, though these studies' goal categories were defined differently than in our study.[39,40] Psychological goals were not commonly

identified in any of these studies. We also found that participants generally had "approach" goals, goals with a positive end state. The pursuit of "avoid" goals may be associated with negative outcomes such as less successful goal pursuit, reduced psychological and physical well-being, and symptoms of physical illness, whereas "approach" goals may be associated with more successful goal pursuit.[34,41-43] The prominence of psychological and approach goals in our study may be related to our population, recruited from Head Start participants. Head Start aims are not only to provide support mechanisms for improved physical health, but also to support improved coping and reduced stress and anxiety. Women who decided to participate in Head Start self-selected into the program and therefore may be more motivated than other women with breast cancer to address their psychological goals or concerns and to be action-oriented. People with cancer with an interest in complementary medicine may have more desire for control over their recovery.[44,45] Overall, however, we found few studies examining the direction or themes of personal goal content of people with any type of cancer. In addition, comparisons to existing literature are difficult given the differences in population characteristics (e.g. cancer type, time since diagnosis) and in analytic methods. Our study contributes to the literature, but more studies using similar methods are necessary to understand the types of goals set by women with a recent breast cancer diagnosis and the progress that women are able to make on various types of personal goals.

5.7.3 Dimensions of personal goals

Our study is the first to publish results of a wide range of personal goal dimensions among women with breast cancer. Compared to a few studies that have measured perceptions of likelihood of goal success, our findings are consistent with a study that found that people with cancer may perceive that the likelihood of success of their goals increases over time,[40] but less

consistent with one that found that women's perceptions of goal attainability (a similar but different concept) were low over six months following breast cancer surgery.[46]

Selection, Optimization and Compensation model is often applied in research on aging.[47] In this study, we applied it in a (to the best of our knowledge) less-often used way to goal pursuit during a major health event. SOC theory can help identify several factors that contribute to an individual's ability to take action on their goals when faced with a loss of personal resources, as is common when dealing with a cancer diagnosis. These include the ability to focus one's attention on, devote time to, and draw on the help of others towards one's goals.[16] We would therefore expect to see positive associations between related dimensions and goal pursuit. Descriptively, median scores for attention, time adequacy and support from others were quite high in our study (≥7.50 out of 10 at all time points), but median goal pursuit scores were more modest (3.25 and 3.50 out of 5, respectively). In addition, score ranges for support from others and time adequacy were large, indicating heterogeneity in perceptions of important personal goals. Our ability to comment on any effect on goal pursuit is limited: a quantitative analysis of goal pursuit scores and goal dimensions was planned but not conducted due to the small sample size.

After the end of Head Start (T2), feelings of stress were lowest and feelings of happiness and perceptions of time adequacy and likelihood of goal success highest. As hypothesized, ratings of self-identity and support from others increased over time; however, average autonomy scores were 10.0 across all time points and did not increase over time as hypothesized. Our hypotheses were based on changes we expected to see given the aims and activities of Head Start. However, our sample size was small, which limits our ability to draw conclusions about the effect of Head Start on the ways that participants thought and felt about their goals. They may also have been influenced by breast cancer treatment effects, which we did not measure in this study.

5.7.4 Barriers and enablers of goal pursuit

Overall, we found that most participants were able to make modest progress on the goals that they considered important but were not able to pursue many of their goals as successfully as they had hoped. Some participants were relatively consistent in the extent to which they pursued all six of their important goals, while others pursued some goals more than others. Five of the six women with complete follow-up had at least one goal for which they rated their pursuit 4.0 or 5.0 at both T2 and T3. Participants mentioned breast cancer treatment and the new commitments on their time and energy as a barrier to goal pursuit. This suggests that, with limited resources available, it may not be possible for women undergoing breast cancer treatment to successfully pursue six goals, but it seems possible for women to identify at least one important goal that they can pursue with a relatively high degree of success. Health goals had the highest average pursuit scores (sample-specific pursuit median = 4.0 at T2 and T3, $n = 5$) and goals related to ordering one's affairs had the lowest scores (sample-specific pursuit median = 1.5 at T2, 2.0 at T3, $n = 1$).

In our exploratory, post-hoc analysis, we also found a potential inverse relationship between the number of major changes to participants' lists of important goals and median goal pursuit scores. Participants with fewer major changes to their lists of important goals had higher median goal pursuit scores. Although our sample size was small and we did not observe a linear relationship, these data suggest that participants who were able to identify their important personal goals and maintain them over a period of three to four months believed they had pursued their goals more successfully. Goals that were added at T2 were deemed to be much less successfully pursued, with lower pursuit scores at T3 than goals identified at T1. The reasons for this are unknown, but time may have been a contributing factor. Participants had approximately six to thirteen weeks less to pursue the goals added at T2. This is, however, not consistent with several studies that have examined the adjustment of goal pursuit among women with breast cancer in the

face of barriers.[48-51] These studies have found that the ability to disengage from goals that are deemed unattainable and engage in new goals has been positively associated with well-being and negatively associated with anxiety and depressive symptoms. However, these studies did not measure pursuit of new goals or examine the characteristics of goals that were added later, and one of them found that engaging in new goals while awaiting chemotherapy, a time of uncertainty, may be associated with greater anxiety.[50] Among women with breast cancer, goal interference may also have a negative effect on well-being.[21,47] Such interference may have prevented the pursuit of newly-added goals.

On the other hand, there did not appear to be a difference between pursuit scores of goals removed at T2 (sample-specific median = 2.75) and that for all goals at T2 (3.25), but pursuit of goals removed at T3 was generally higher than that of all goals at T3 (sample-specific median = 5.00 and 3.50, respectively). Goal pursuit scores measured how much participants felt that they were able to pursue their goals, not the degree of success of their pursuit. The pursuit scores may indicate that participants removed goals once attained and no further progress was desired or that, despite high pursuit levels, they were unable to attain certain goals and chose to discontinue their pursuit. Other study data may support the second scenario. One, removed goals may have been more emotionally taxing than other important goals. At T2, participants felt more fear and stress about the goals they later removed at T3 (sample-specific medians = 3.50 and 4.00 respectively) than about their goals in general (sample-specific medians = 0.00 for both dimensions). Two, all personal goals that were modified at T2 were removed at T3. Although the pursuit scores for modified goals did not appear to differ from scores for goals overall, it may be that goal modification represented an attempt to adjust a difficult goal before removing the goal all together. Participants felt more scared and stressed about goals modified at T2 (sample-specific medians = 5.00 and 8.00, respectively) than they did about their goals overall at T2 (0.00 for both

dimensions). Finally, the likelihood of success for goals removed at T3 was rated a little lower than overall goals at T3 (sample-specific medians = 7.50 and 9.00 respectively). However, our sample size was small and we are unable to determine the significance of variations in effect sizes. This was a post-hoc, exploratory analysis and further research would be required to determine any association between goal changes and goal pursuit.

Given the small number of participants, we did not conduct a planned analysis of goal dimension scores and goal pursuit scores that may have provided additional insight on the characteristics of the goals that were most successfully pursued. Future research may examine these various aspects of goal characteristics to better understand what kinds of personal goals and goal systems women with a recent cancer diagnosis feel more able to successfully pursue during an uncertain time.

Our study identified several barriers and enablers of personal goal pursuit. We identified twice as many enablers (10) as we did barriers (5), perhaps due in part to having one interview where only the most successfully pursued goal was discussed. To our knowledge, previous studies have not examined enablers of personal goal pursuit among women with breast cancer. In our study, participants identified several enablers that were related to shifts in thinking or adaptations to situations, e.g. some women spoke about making conscious efforts to dedicate time and resources to a highly pursued goal; some saw cancer as motivation for improved health in the future; and some changed their definitions of goal progress during goal pursuit or the way in which one thought about her control over the goal. The latter two examples of enablers align with preliminary findings from a study by Peterman and Lecci on the personal goals of women with breast cancer undergoing treatment.[19] They found that many women shifted the characteristics of their goals (e.g. by shifting the timeframe for attainment) or by replacing a goal with a new project. Two women in our study identified goal facilitation as an enabler of their goal pursuit. We

did not examine how the pursuit of goals within an individual's goal system enabled or hindered each other, but previous research suggests that having goals that enable each other may facilitate goal pursuit.[52]

Cancer and its treatment hindered goal pursuit for all participants in our study and has been identified as a reason for goal interference in previous studies.[21,38] In our study, however, we observed that the experience of cancer also enabled goal pursuit for some women. Helping women to identify the resources and experiences available may help to enable goal pursuit. Some studies have identified strategies that people with cancer use to adjust their personal goals[53,54] The methods that people with cancer use to adjust or think about their goals can have an impact on psychological well-being. Interventions that use effective strategies to help women identify and adjust goals that can be pursued while undergoing treatment may facilitate more successful goal pursuit, and mitigate the negative effects of cancer-related interference on well-being.[21,46,54,55] Further studies are needed to more fully understand the barriers and enablers that women face following a breast cancer diagnosis.

We found that the Head Start program was an enabler for most participants. Many of the ways that Head Start helped participants was in teaching skills, knowledge or practices that participants then used in their goal pursuit efforts. The social peer support was also identified as an enabler. Participants spoke about the value of being in a group of women experiencing similar situations and benefitting from the perspectives and advice of others. How these aspects specifically enabled goal pursuit was not discussed. We did, however, ask participants directly about any potential impact of Head Start and complementary therapies, whereas other enablers were generated by participants. It is possible that participants felt social desirability created undue pressure on participants to cite aspects of Head Start as enablers of their goal pursuit and that, unprompted, some or all of the participants may not have identified participation in Head Start as

an enabler of their goal pursuit. We tried to mitigate responses based on social desirability: participants knew that their individual responses would not be shared with the OICC, and a few participants did indicate that Head Start did not enable their goal pursuit or that they were not sure that it did. Several participants did identify helpful aspects of Head Start, and we believe that there is potential for a more comprehensive study into the ways in which the social support of Head Start affects the personal goal-setting and pursuit of women participating in the program. Such information would enhance the literature on effective interventions on personal goal pursuit for women with breast cancer.

5.7.5 Strengths and limitations

This study was conducted in collaboration with a community-based health organization, in efforts to ensure that the study would focus on aspects relevant and useful to the target population. This collaboration improved the study design and analysis by adding the expertise of people working directly with women with breast cancer.

Our mixed-methods approach made for a more nuanced examination of the personal goals and personal goal pursuit. Quantitative ratings and use of published, well-established methodologies such as Personal Projects Analysis[5] and thematic categorizations of personal goals[17] allowed us to compare personal goals that are idiographic in nature and for future studies to compare their findings to ours. Qualitative data provided richer exploration of barriers and enablers to goal pursuit.

A further strength of this study is that it is one of only a few that have focused on women recently diagnosed with breast cancer: the average time between diagnosis and baseline was approximately 2.5 months. This can be a time characterized by uncertainty and change. We experienced some difficulty recruiting and the dropout of two of eight participants. These are the

realities of conducting research with women with a recent cancer diagnosis; however, conducting research with women at this time contributes important knowledge to building and enhancing effective and timely support interventions.

This study also has limitations. The most notable is our unanticipated small sample size. Head Start enrollment was much lower than expected, limiting the pool of potential study recruits. We were therefore unable to conduct several planned analyses and data had to be collapsed to avoid identifying participants. Community-based research, however, is subject to factors that cannot be controlled. Our small sample means that we have very few representatives across important participant and medical characteristics, such as age and diagnostic stage. This overemphasizes certain perspectives and underrepresents or excludes other perspectives and warrants caution in the conclusions we draw while nevertheless pointing to opportunities for future research building on these findings.

Although Head Start is offered free of charge, it is not known to every woman diagnosed with breast cancer in the Ottawa area. It therefore is likely to attract participants who already have an interest in complementary and integrative medicine. Women with breast cancer who pursue complementary or alternative medicine may have different sociodemographic characteristics than the population of women with breast cancer at large.[22] Also, this study was subject to a risk of selection bias. It is possible that those who joined the study faced fewer barriers to goal pursuit than those who did not: barriers to goal pursuit may also have been barriers to study participation. Women who experienced negative physical or psychological effects of breast cancer or its treatment or have more time commitments may have been less likely to participate in this study, been less likely to successfully pursue their personal goals, and identified different barriers and enablers of their goals.[19,21,56]

We did not measure goal importance as a dimension, although we asked participants to select their most important goals. As such, we know that the six selected goals were relatively more important to participants than the other goals identified at T1 but we were unable to quantify the importance of each of the important goals relative to each other or explore potential relationships between goal importance and goal pursuit. We would have needed a much larger sample size to conduct any analysis of relationships between any goal dimension and goal pursuit; however, a sample adequately large enough for such analysis was unavailable given our source population. In addition, given the time and physical resources required of women undergoing breast cancer treatment, we wanted to limit the number of dimensions presented to participants; ideally we would have included all relevant standard dimensions recommended by Personal Projects Analysis.[5]

This study was also subject to a risk of response bias, affecting our ability to generalize results. All data was self-reported. The perspectives of the interviewer may have shaped the barriers and enablers identified in this study. We attempted to mitigate this risk of bias by using an interview guide to standardize the qualitative interviews as much as possible. Interview transcripts were reviewed by AC for possible introduction of bias and adjusted as needed. A subset of interview transcripts were reviewed by a second author (JP), and pre-existing qualitative methodological approaches were used to analyze the data.[36,37] Not all participants were asked as planned about the influence of four factors relevant to the population: breast cancer-related symptoms, treatment-related effects, Head Start participation, and use of complementary therapy. This was due to time constraints, interviewer judgment about the appropriateness of such questions, and interviewer error. Although many of these influences were discussed by participants without being directly asked by the interviewer, greater consistency in interviewing may have yielded additional information that could have strengthened our understanding of how

these factors hindered or enabled goal pursuit. The identification of barriers and enablers and categorization of goal content was subjective. We recognize that other researchers, or participants themselves, with a more thorough knowledge about their own goals, may have categorized the goals differently than we have. Definitions helped with categorization consistency. Sometimes participants elaborated on a goal in interviews, but because only a few goals were discussed in interviews we did not use interview data to assist with goal content categorization.

5.8 CONCLUSION

Despite the uncertainty that can accompany a breast cancer diagnosis, studies suggest that the successful pursuit of goals may be associated with positive psychological well-being and unsuccessful pursuit with higher distress.[47,54] Few published studies have examined the personal goals set by women with breast cancer. This study contributes new, preliminary evidence on the personal goals and goal pursuit of women with breast cancer who are participating in an integrative oncology education and support program. We found that there was a large range in the degree to which women pursued their goals and identified several enablers and barriers to those goals. Our sample size was small, but our study presents several avenues for future research about personal goal pursuit among this population. Moreover, the barriers and enablers to goal pursuit identified by our study could be addressed by new or existing interventions to support women in pursuing their important goals. Integrative oncology programs, in particular, with a focus on patient-centred care, could use these findings to develop interventions that use personal goal-setting to help women identify motivations that are important to them. Although health and psychological goals were most frequently identified, women in our study identified a variety of personal goals across multiple life domains that were important to them. This suggests that, in

addition to a focus on health, other aspects of life remain important to women and are important to consider in the provision of patient-centred care. We recommend future studies to further understand these aspects of personal goal-setting and pursuit that can be used in support and care programs for women facing breast cancer treatment.

5.9 FIGURES AND TABLES

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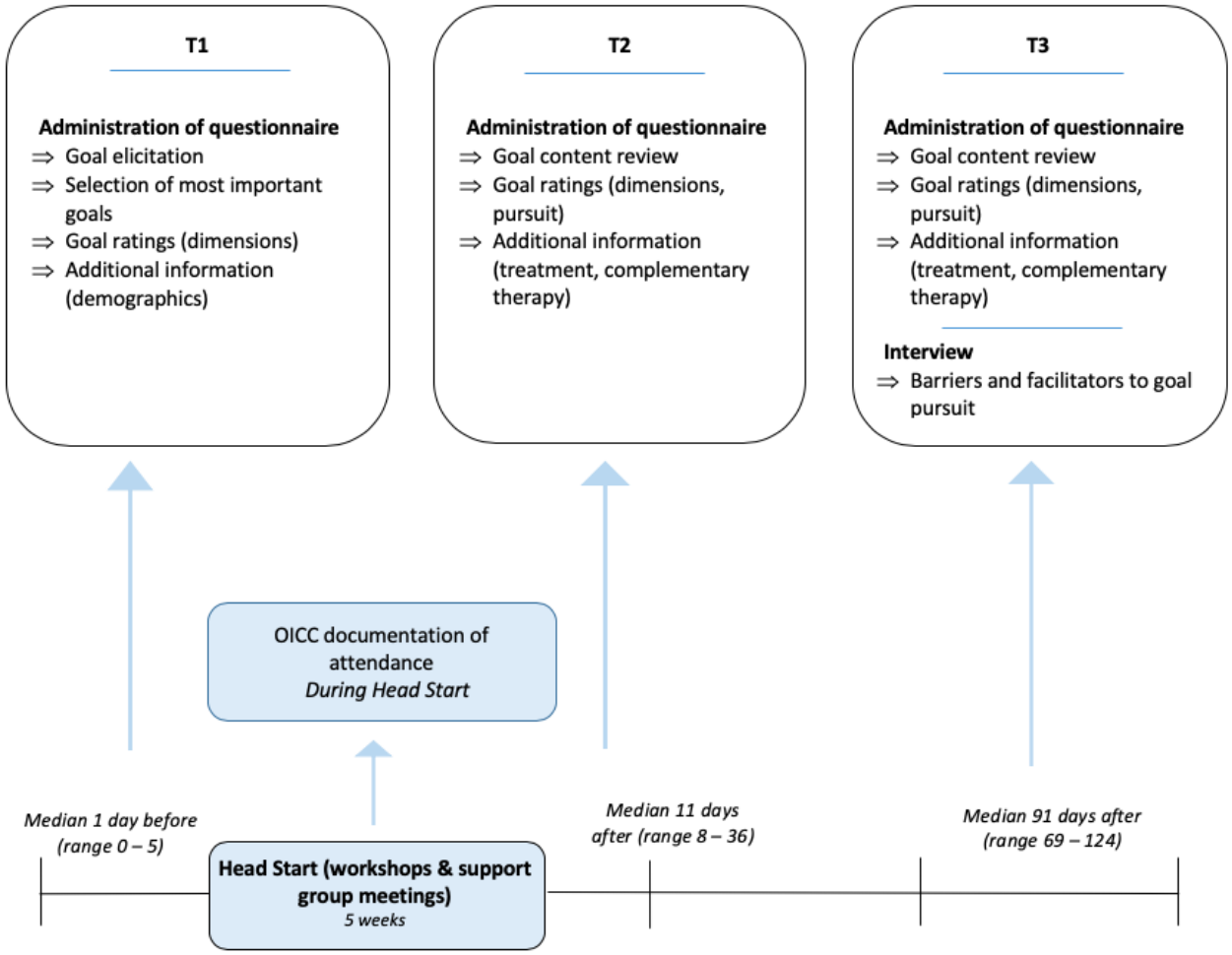


Figure 1. Study elements

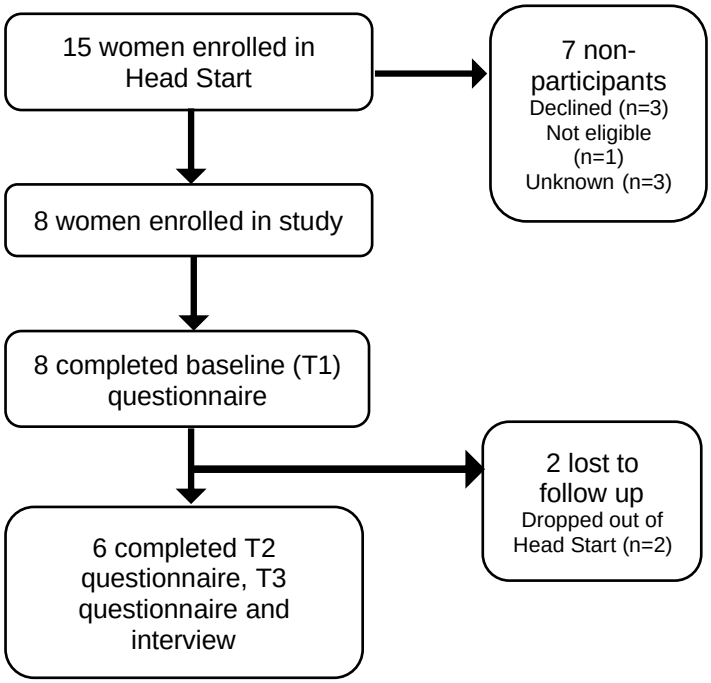
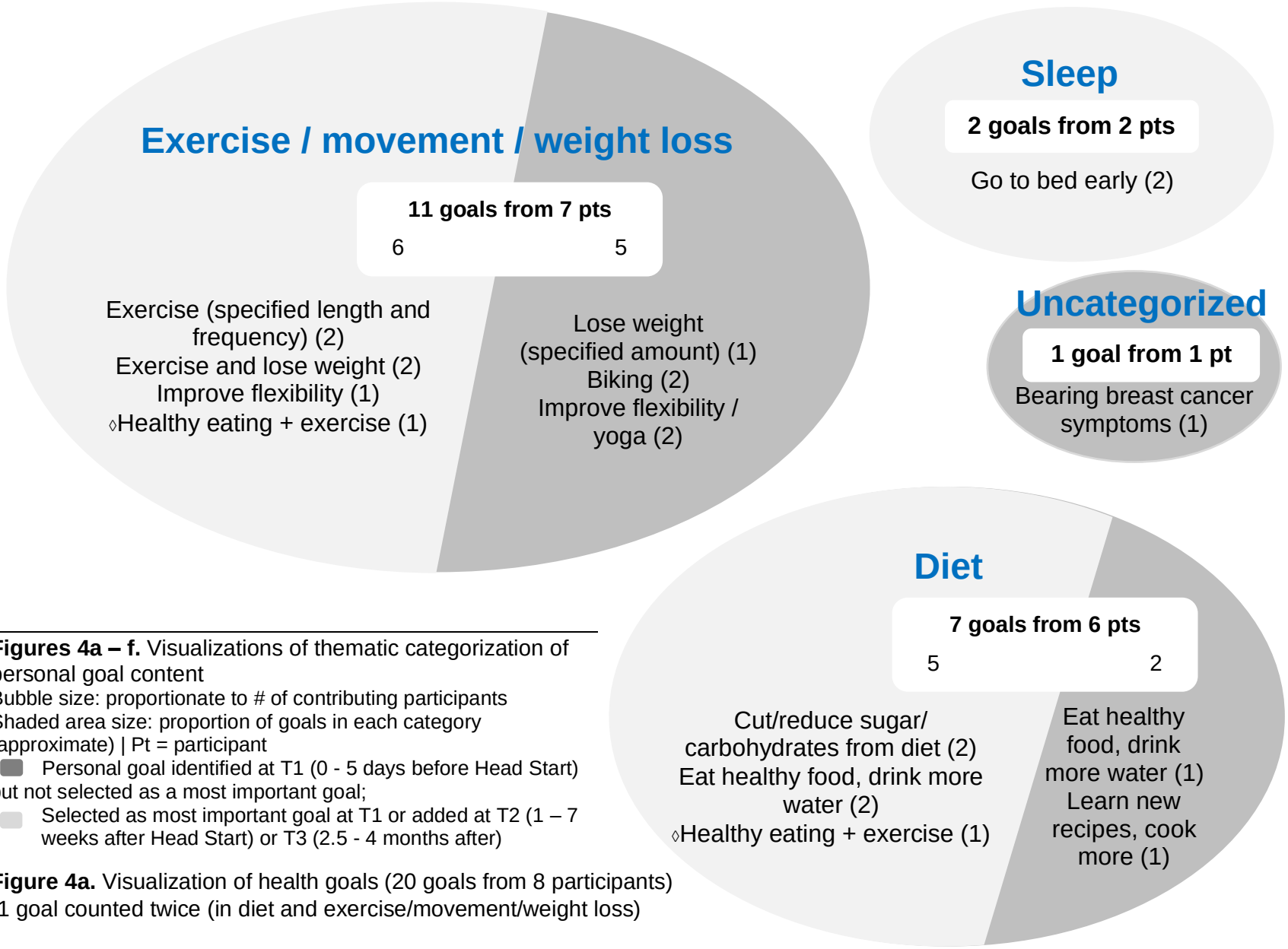


Figure 2. Participant flow diagram
T1 = 0 - 5 days before Head Start; T2 = 1 – 7 weeks after; T3 = 2.5 - 4 months after

Participant	T1	T2	T3	Goal changes
1	Health *	5	4	None
	Health *	4	5	
	Psychological *	5	3	
	Psychological *	5	5	
	Social *	3	5	
	Social *	5	5	
	Health			
	Health			
	Psychological			
	Social			
	Achievement			
	Leisure			
4	Health *	3	4	T2: 2 goals removed, 2 goals added, 1 goal modified T3: 2 goals removed, 2 goals added, 1 goal modified
	Health *	xxxxx 2 xxxxx	xxxxxxxxxx	
	Psychological *	5 △	xxxxx 5 xxxxx	
	Psychological *	xxxxx 2 xxxxx	xxxxxxxxxx	
	Ordering affairs *	2	3	
	Ordering affairs *	1	1	
		Psychological	3 △	
		Psychological	xxxxx 2 xxxxx	
			Health	
			Psychological	
	Health			
	Psychological			
	Social			
	Social			
	Social			
	Leisure			
5	Health *			Not applicable
	Health *			
	Social *			
	Social *			
	Social *			
	Ordering affairs *	Dropout		
	Health			
	Health			
	Social			
	Leisure			
	Leisure			
7	Psychological *	3	2	T2: 1 goal removed, 1 goal added, 1 goal modified T3: 1 goal removed
	Psychological *	5	5	
	Psychological *	5	4	
	Psychological *	3 △	xxxxx 5 xxxxx	
	Psychological *	3	4	
	Social *	xxxxx 4 xxxxx	xxxxxxxxxx	
		Social	2	

Participant	T1	T2	T3	Goal changes
2	Health *	5	4	T2: 1 goal removed, 1 goal added
	Psychological *	4	3	
	Psychological *	2	2	
	Social *	3	4	
	Achievement *	3	2	
	Leisure *	xxxxx 2 xxxxx	xxxxxxxxxx	
		Leisure	1	
	Social			
	Achievement			
	Achievement			
	Leisure			
	Leisure			
	Leisure			
3	Health *	4	4	T3: 1 goal removed, 1 goal added
	Psychological *	4	5	
	Psychological *	5	5	
	Achievement *	5	xxxxx 5 xxxxx	
			Leisure	
	Achievement *	2	4	
	Leisure *	5	4	
	Health			
	Psychological			
	Achievement			
	Achievement			
	Leisure			
	Leisure			
6	Health *	1 △	xxxxx 1 xxxxx	T2: 1 goal removed, 1 goal added, 2 goals modified T3: 5 goals removed
	Health *	3	xxxxx 1 xxxxx	
	Psychological *	4 △	xxxxx 1 xxxxx	
	Psychological *	xxxxx 4 xxxxx	xxxxxxxxxx	
		Social	xxxxx 3 xxxxx	
	Psychological *	1	xxxxx 1 xxxxx	
	Social *	3	2	
	Health			
	Psychological			
	Social			
	Social			
	Achievement			
	Ordering affairs			
8	Health *			Not applicable
	Health *			
	Psychological *	Dropout		
	Social *			
	Social *			
	Leisure *			

Figure 3. Overview of participants' personal goals over time
T1 = 0 - 5 days before Head Start; T2 = 1 – 7 weeks after; T3 = 2.5 - 4 months after
xxxx = goal removed; △ = goal modified; ▭ = goal retained; Approach; Maintain; Avoid; * Personal goal selected as one of important goals
Numbers at T2 and T3 indicate goal pursuit scores = 1 "not at all" to 5 "as fully as I could"



Figures 4a – f. Visualizations of thematic categorization of personal goal content
Bubble size: proportionate to # of contributing participants
Shaded area size: proportion of goals in each category (approximate) | Pt = participant
Personal goal identified at T1 (0 - 5 days before Head Start) but not selected as a most important goal;
Selected as most important goal at T1 or added at T2 (1 – 7 weeks after Head Start) or T3 (2.5 - 4 months after)

Figure 4a. Visualization of health goals (20 goals from 8 participants)
◊1 goal counted twice (in diet and exercise/movement/weight loss)

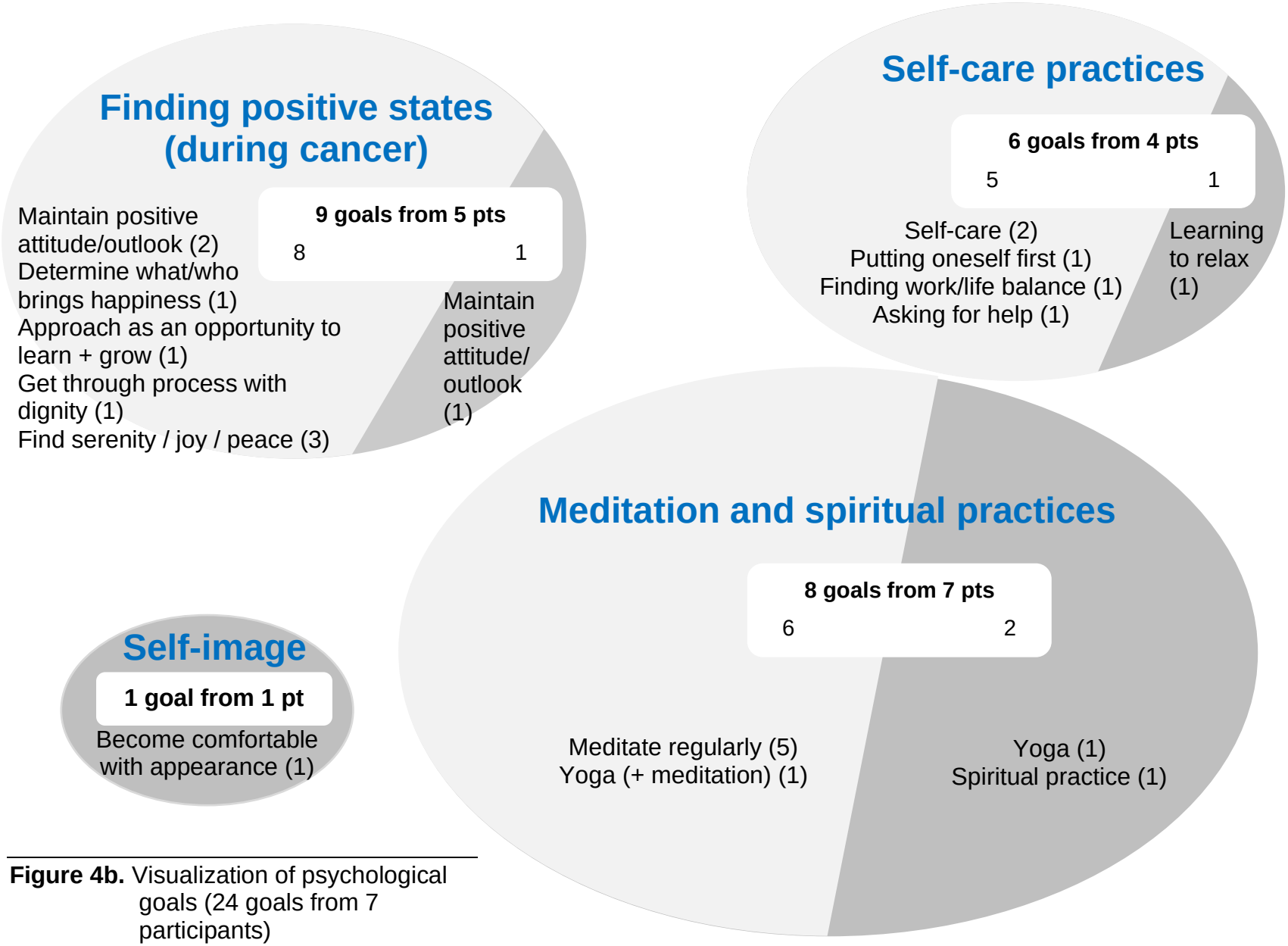


Figure 4b. Visualization of psychological goals (24 goals from 7 participants)

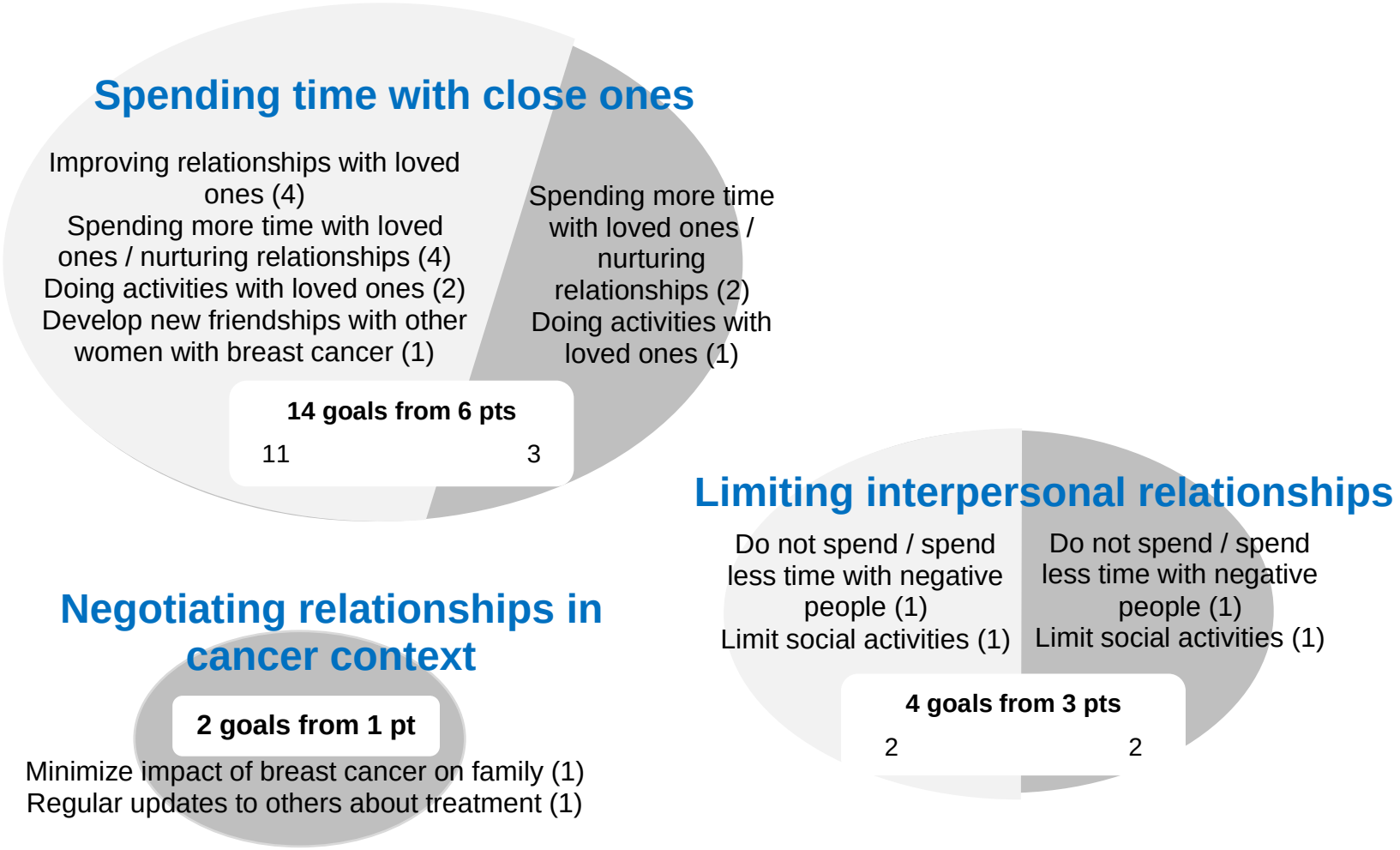


Figure 4c. Visualization of social goals (20 goals from 7 participants)

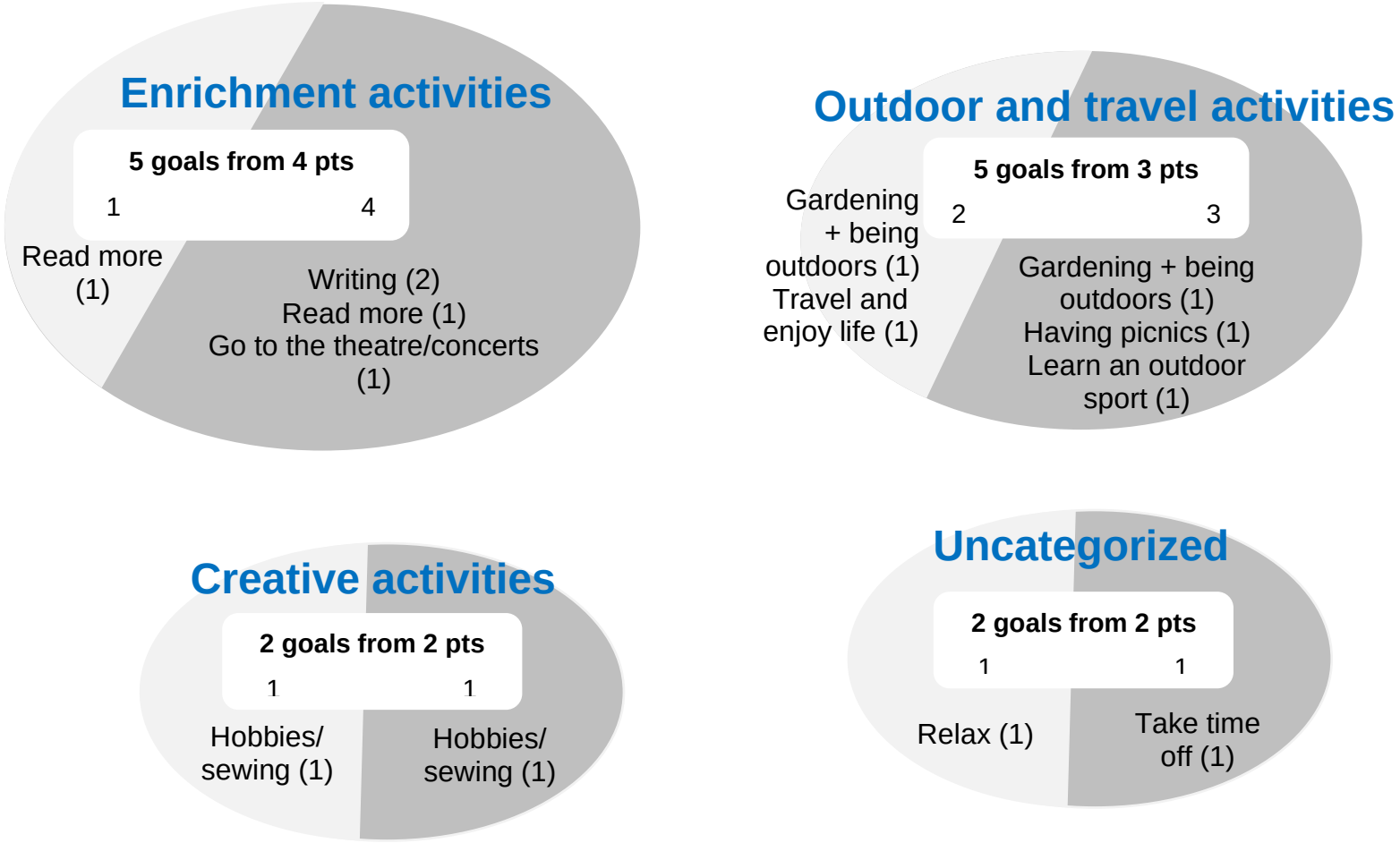


Figure 4d. Visualization of leisure goals (14 goals from 6 participants)

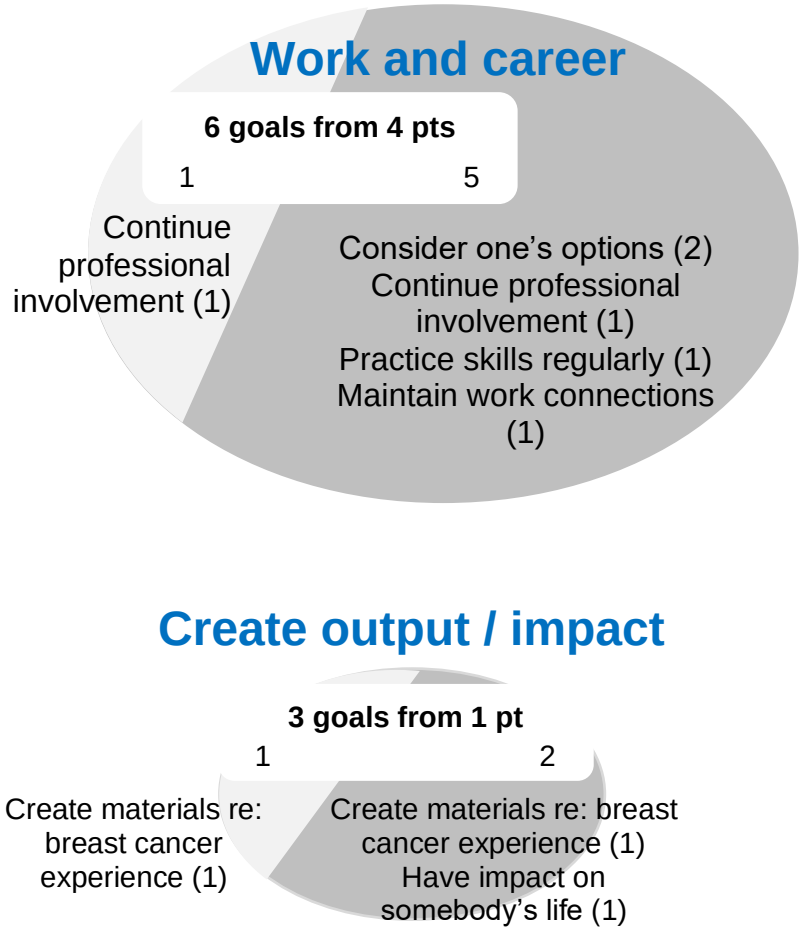


Figure 4e. Visualization of achievement goals (9 goals from 4 participants)

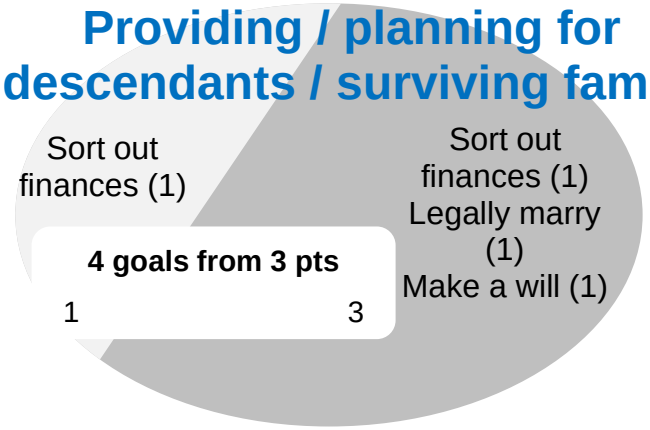


Figure 4f. Visualization of "ordering one's affairs" goals (4 goals from 3 participants)

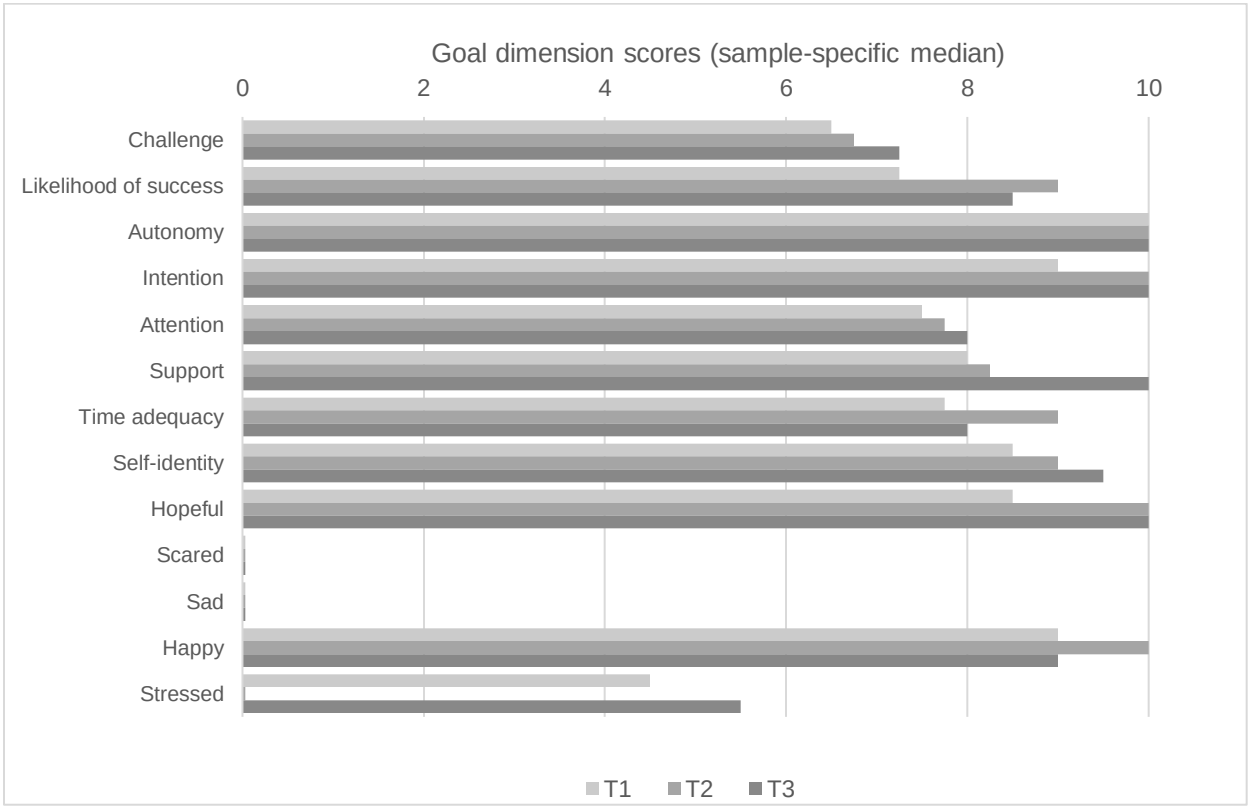


Figure 5. Personal goal dimension ratings

Personal goal dimensions rated on a scale of 0 to 10. A higher rating indicates the strength of thoughts or feelings about the personal goals. For each participant, the median score for each dimension was calculated across all her (up to six) important goals at each time point (participant-specific median), and the median of the participant-specific medians calculated (sample-specific medians).
T1 = 0 - 5 days before Head Start; T2 = 1 – 7 weeks after; T3 = 2.5 - 4 months after
T1 n=8; T2 n= 6; T3 n=6 except hopeful, scared, sad, happy and stressed n=5

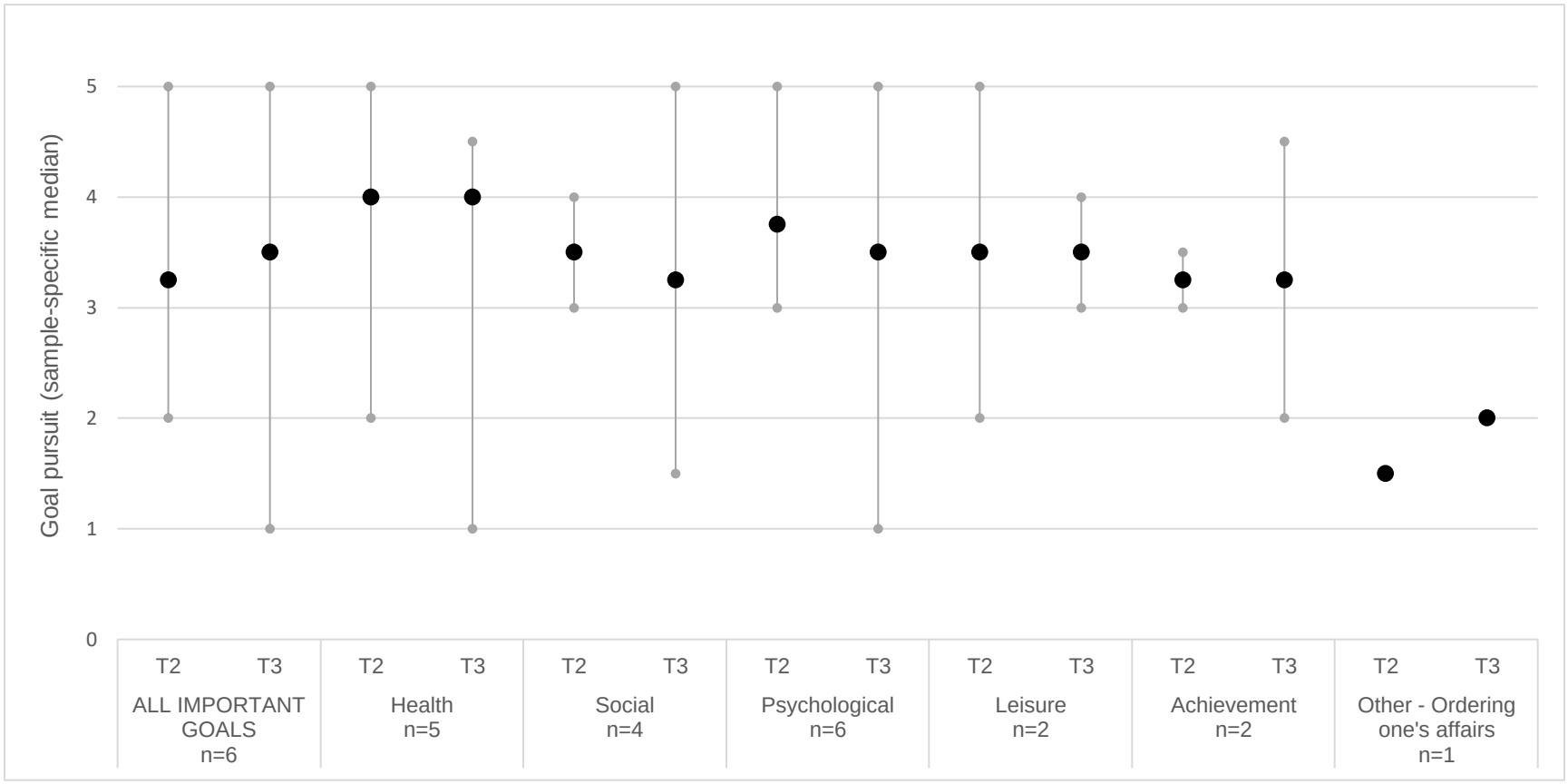


Figure 6. Personal goal pursuit scores – overall and by thematic category

Personal goal pursuit rated on a scale of 1 “not at all” to 5 “as fully as I could”
T2 = 1 – 7 weeks after Head Start; T3 = 2.5 - 4 months after
• = Sample-specific median. For each participant, the median pursuit score for each category was calculated across all her important goals at each time point (participant-specific median), and the median of the participant-specific medians calculated (sample-specific medians).
•—• = Range limits of sample-specific medians

Table 1. Data sources and measurement

Variable of interest	Source of data	Method of measurement
Participation in Head Start	Head Start attendance records	Yes/no. For “yes”, number of workshop days and number of support group meetings attended will be counted
Barriers and facilitators to goal pursuit, including Head Start factors, cancer-related symptoms, treatment factors, and complementary therapy factors	Participants	Semi-structured, face-to-face interviews (participants)
Personal goal elicitation	Participants	PPA-based goal elicitation
Personal goal pursuit ratings	Participants	Ratings on a 5-point scale
Personal goal dimensions of: challenge, likelihood of success, autonomy, intention attention, support, time adequacy, self-identity, hopeful, scared, sad, happy, and stressed	Participants	PPA-based goal ratings on a 11-point scale
Demographic variables	Participants	Participant assessment. Categorical: current living situation, highest education level completed, household income (annual, Canadian dollars), breast cancer stage. Continuous: age (years), time since diagnosis (days)
Conventional cancer treatment currently received	Participants	Participant assessment (y/n)
Complementary therapy currently received	Participants	Participant assessment (y/n)

PPA: Personal Projects Analysis

Table 2. Participant characteristics

	Median (range) or n
At baseline (n=8)	
Age (years)	50 (late 30s – early 60s)
Time since diagnosis (days) $	75 (44 -100)
Living situation	
Living with ≥1 family member	8
Level of education	
Post-secondary certificate, diploma, or university degree	6
Some high school or high school diploma	2
Household income, Canadian dollars	
$30,000 - $90,000	3
$90,001 or above	4
No answer	1
Breast cancer stage	
0 to I	<5
II to III	5
Unknown or unclear	<5
Head Start participation	
Attendance at full-day sessions (n=8)	8
Attendance at evening support group meetings (n=5)	
3 or 4 sessions	4
1 or 2 sessions	4
At first follow-up (T2) (n=6)	
Receiving complementary therapy	6
Receiving conventional cancer treatment	6
At second follow-up (T3) (n=5)	
Receiving complementary therapy	4
Receiving conventional cancer treatment	4

$ One participant provided only the month of diagnosis. This median assumes the longest amount of time since diagnosis (on the first date of the month).

*No data on attendance at 3rd weekly session in September 2017 round. Two participants counted as having attended two sessions may have actually attended three.

Data categories have been collapsed to mitigate identifying details.

Table 3. Descriptive statistics of participants' personal goals at baseline

	Median (range) per participant *n=8*
Goals identified	12 (6 – 12)
Goal content theme	
Psychological	3 (0 – 5)
Social	2.5 (0 – 4)
Health	2.5 (0 – 4)
Leisure	1 (0 – 4)
Achievement	0.5 (0 – 4)
Ordering affairs	0 (0 – 2)
Goal content direction	
Approach	10 (4 – 11)
Avoid	1 (0 – 2)
Maintain	1 (0 – 2)

Table 4. Descriptive statistics of participants' most important goals

	Median (range) per participant		
	T1 *n = 8*	T2 *n = 6*	T3 *n = 6*
Goals identified†	6 (6)	6 (6)	6 (1 – 6)
Goals, by theme†			
Psychological	2 (0 – 5)	2 (2 – 5)	2 (0 – 4)
Health	2 (0 – 2)	1 (0 – 2)	1 (0 – 2)
Social	1 (0 – 3)	1 (0 – 2)	1 (0 – 2)
Achievement	0 (0 – 2)	0 (0 – 2)	0 (0 – 1)
Ordering affairs	0 (0 – 2)	0 (0 – 2)	0 (0 – 2)
Leisure	0 (0 – 1)	0 (0 – 1)	0 (0 – 2)
Goals, by direction†			
Approach	5 (4 – 5)	5 (5 – 6)	5 (1 – 6)
Avoid	0 (0 – 1)	0 (0 – 1)	0.5 (0 – 1)
Maintain	1 (0 – 1)	1 (0 – 1)	0 (0 – 1)
Goal dimension scores§			
Challenge	6.50 (3.00 – 10.00)	6.75 (1.00 – 8.00)	7.25 (1.00 – 8.00)
Likelihood of success	7.25 (4.00 – 9.00)	9.00 (5.50 – 9.00)	8.50 (5.50 – 10.00)
Autonomy	10.00 (7.00 – 10.00)	10.00 (6.50 – 10.00)	10.00 (8.00 – 10.00)
Intention	9.00 (7.50 – 10.00)	10.00 (8.00 – 10.00)	10.00 (1.00 – 10.00)
Attention	7.50 (7.00 -10.00)	7.75 (6.50 – 10.00)	8.00 (1.00 -10.00)
Support	8.00 (2.00 – 10.00)	8.25 (4.00 – 10.00)	10.00 (7.00 – 10.00)
Time adequacy	7.75 (5.00 – 10.00)	9.00 (2.00 – 10.00)	8.00 (2.00 – 10.00)
Self-identity	8.50 (6.50 – 10.00)	9.00 (6.50 – 9.50)	9.50 (5.00 – 10.00)
Hopeful	8.50 (6.00 – 10.00)	10.00 (8.00 – 10.00)	10.00 (10.00)*
Scared	0.00 (0.00 – 6.00)	0.00 (0.00 – 7.50)	0.00 (0.00 – 5.50)*
Sad	0.00 (0.00 – 8.00)	0.00 (0.00 – 4.00)	0.00 (0.00 – 6.00)*
Happy	9.00 (0.00 – 10.00)	10.00 (5.50 – 10.00)	9.00 (6.50 – 10.00)*
Stressed	4.50 (0.00 – 9.00)	0.00 (0.00 – 7.50)	5.50 (0.00 – 7.00)*
Goal changes†			
Added goals	n/a	1.0 (0.0 – 2.0)	0.0 (0.0 – 2.0)
Removed goals	n/a	1.0 (0.0 – 2.0)	1.0 (0.0 – 5.0)
Modified goals	n/a	0.5 (0.0 – 2.0)	0.0 (0.0 – 1.0)

T1 = 0 - 5 days before Head Start; T2 = 1 – 7 weeks after; T3 = 2.5 - 4 months after
*n=5; † Number (maximum 6); §Scale 0 – 10 (higher scores indicate greater participant perception of a dimension, e.g. 10 = extremely challenging and 0 = not challenging at all)

Table 5. Goal pursuit descriptive statistics

		Goal pursuit scores§ Sample-specific medians (range)	
Goal categories	n	T2	T3
Important goals	6	3.25 (2.00 – 5.00)	3.50 (1.00 – 5.00)
Content theme			
Health	5	4.00 (2.00 – 5.00)	4.00 (1.00 – 4.50)
Social	4	3.50 (3.00 – 4.00)	3.25 (1.50 -5.00)
Psychological	6	3.75 (3.00 – 5.00)	3.50 (1.00 – 5.00)
Leisure	2	3.50 (2.00 – 5.00)	3.50 (3.00 – 4.00)
Achievement	2	3.25 (3.00 – 3.50)	3.25 (2.00 – 4.50)
Ordering affairs	1	1.50	2.00
Goals removed at T2	4	2.75 (2.00 – 4.00)	2.75 (2.00 – 5.00)
Goals added at T2		n/a	2.25 (1.00 – 3.50)
Goals modified at T2	2	3.00 (2.50 – 5.00)	3.00 (1.00 – 5.00)
Goals removed at T3	3	5.00 (1.00 – 5.00)	4.25 (1.00 – 5.00)

T2 = 1 – 7 weeks after Head Start; T3 = 2.5 - 4 months after

§Scale of 1 (*not at all*) to 5 (*as fully as I could*)

Table 6. Goal dimensions of changed goals

	Sample-specific medians (range) per participant					
	Removed		Added		Modified	
	At T2† *n*=4	At T3† *n*=3	T2 *n*=4	T3 *n*=2	T2 *n*=3	T3 *n*=1
Goal dimension scores§						
Challenge	5.50 (4.00 – 7.00)	7.25 (3.00 – 9.00)	7.50 (6.00 – 8.00)	1.50 (0.00 – 3.00)	7.00 (6.50 – 9.00)	10.00
Likelihood of success	8.75 (5.00 – 10.00)	7.50 (6.00 – 10.00)	6.75 (6.00 – 8.00)	8.75 (7.50 – 10.00)	7.00 (6.00 – 9.00)	4.00
Autonomy	10.00 (6.00 – 10.00)	10.00 (7.00 – 10.00)	9.50 (9.00 – 10.00)	8.25 (6.50 – 10.00)	10.00 (7.00 – 10.00)	10.00
Intention	8.50 (7.50 – 10.00)	9.50 (8.00 – 10.00)	8.75 (8.00 – 10.00)	9.75 (9.50 – 10.00)	9.00 (8.00 – 10.00)	7.00
Attention	7.50 (6.50 -10.00)	8.00 (6.00 - 10.00)	6.50 (6.00 – 7.50)	9.25 (8.50 – 10.00)	8.00 (5.50 -8.00)	6.00
Support	7.25 (0.00 – 10.00)	7.50 (2.00 – 10.00)	6.50 (5.00 – 10.00)	9.00 (8.00 – 10.00)	7.00 (5.50 -8.00)	5.00
Time adequacy	7.75 (6.00 – 9.00)	9.00 (2.00 – 10.00)	6.50 (5.00 – 10.00)	7.75 (5.50 – 10.00)	10.00 (2.00 – 10.00)	0.00
Self-identity	6.50 (5.00 – 9.00)	8.00 (5.00 – 9.50)	8.50 (5.50 – 9.00)	9.25 (8.50 – 10.00)	8.00 (5.00 – 8.00)	5.00
Hopeful	8.75 (8.00 – 10.00)	10.00 (7.50 – 10.00)	9.50 (8.00 – 10.00)	7.50 (5.00 – 10.00)	10.00 (9.00 - 10.00)	10.00
Scared	6.00 (0.50 – 6.00)	3.50 (0.00 – 7.00)	4.50 (0.00 – 6.00)	5.00 (0.00 – 10.00)	5.00 (0.00 – 7.00)	7.00
Sad	0.50 (0.00 – 6.00)	0.00	1.00 (0.00 – 5.00)	1.50 (0.00 – 3.00)	0.00	6.00
Happy	8.00 (8.00 – 10.00)	8.50 (5.00 – 10.00)	9.25 (6.00 – 10.00)	5.75 (1.50 – 10.00)	8.00 (6.50 – 9.00)	7.00
Stressed	3.75 (0.00 – 6.00)	4.00 (0.00 – 8.00)	5.50 (4.00 – 8.00)	3.75 (0.00 – 7.50)	8.00 (0.00 – 8.00)	3.00

T2 = 1 – 7 weeks after Head Start; T3 = 2.5 - 4 months after

§Scale 0 – 10 (higher scores indicate greater participant perception of a dimension, e.g. 10 = extremely challenging and 0 = not challenging at all).

†Dimensions scored at T1 for goals removed at T2 and at T2 for goals removed at T3

Table 7. Representative quotations illustrating barriers and enablers of personal goal pursuit

Barrier or enabler	Representative quotation
Barriers	
The experience of breast cancer treatment	"I said to someone the other day, 'I have a lump on my breast,' [touches breast] like I was like expecting my breast to be there and it wasn't…right, it's gone. It's got this whole mental fatigue component to it. All that emotional stuff is taxing on your energy. So when it comes time to pursue goals that are not cancer-related, it's hard to have the energy and the motivation, you know, to do it. It has to be a high motivator, you know, to be able to get the energy to do it."
Fear	"For that particular goal, it's also dealing with mortality and death too...so although there is a sense of urgency, it's dealing with something that you don't want to deal with as well…once you're in diagnosis, it's even more important but it's even further away from you wanting to touch it because it's dealing with something that's more possible."
Being more challenging than expected	"It just seemed more challenging than I expected it to be, to be able to focus and to do that for myself. It's not a matter of time, I had time…or opportunity – that wasn't it. It was definitely within me…it just took tremendous energy to shut down all of the chatter in my head and it was easier just to not, you know."
Lack of alignment with self-identity or values	"I think that I assumed…that you do a one-eighty. So, oh you have a diagnosis of whatever, something life threatening or critical. And you're going to go from, in your typical life, you're taking care of everyone else…to oh wow, I'm now going to not worry about other people and I'm going to focus on myself. I mean, is that realistic?...It seems that for me, I thought that I would have been able to do that, but it makes sense that I didn't. Just completely stop taking care of everyone else and then be able to prioritize myself when I never do."
Goal interference/ competing priorities	"My mother she's also she's not well, so I have to help care for her…so that gets in the way too. And all her appointments."
Enablers	
Social supports	"…the people that I've chosen to have around me are those people that understand. So it makes it easier for me to [pursue my goal]…and the response [to my goal pursuit] is just great. It's positive."
Prioritization of the goal	"I'm choosing that [goal] as a priority."
The experience of living with breast cancer and through treatment	"I really identified that [goal] as to be very, very helpful in my recovery."
Changing definition of progress during goal pursuit	"My goal was…me trying to be everything to everybody…to find balance between relationship and friendship and motherhood and work and going through treatment all the same time... I think the word 'life' in that equation would be treatment…I think at the time I might have been thinking personal…So the goal's been really, it wasn't about balance actually. It's probably more about focusing on one thing..."
Identifying and utilizing helpful resources	"I have invested in a hat and I have a sweater so that I'm not exposing myself to too much sun; I had to prep myself to go for walks."
Having time	"Having more time to sit and contemplate helped me to really evaluate my life, and how I was living it and how I'd like to be living it."
Goal facilitation	"I knew why I needed those goals [e.g. meditation] and it's just a matter of keeping them in everyday life to make everyday life less of a stress in general... I'm trying to make the habits that I have attainable so that I can be at work and doing them."
Changing one's thinking	"One of the words that I left out was control, and the sense that I lost control of my life. That it was in other people's hands and there was very

	little that I could do about it, except that then I started to realize that, no, there were things that I could do, and continue to focus on."
Head Start	"I think being willing to be open in the group, to talking about how I was feeling and what my issues were. And as we walked through all of it and to be willing to listen to suggestions, advice, any of that that came from the group, not just the leaders but any of the women in the group…I think some of the things that I've come out of it learning is the acceptance that I don't have control over anything. I can do what I can do but outside of that…"
Complementary therapies	"Some of the therapies are looking at patterns from your childhood, and for me…it's going back and healing those patterns to enable me to be strong enough to set boundaries and know that I'll be OK, that I'll be loved and accepted…I can step more fully into my power and embrace my life and know I'm worthy of as much as everybody else. And so in that sense it's helped me."

5.10 REFERENCES FOR CHAPTER 5

1. Ryan RM, Deci EL. Self-determination theory and the facilitation of intrinsic motivation, social development, and well-being. Am Psychol. 2000;55:68–78.

2. Austin JT, Vancouver JB. Goal constructs in psychology: Structure, process, and content. Psychol Bull. 1996;120:338–75.

3. Elliot A, Thrash T. Achievement goals and the hierarchical model of achievement motivation. Educ Psychol Rev. 2001;13:139–56.

4. Emmons RA. Personal strivings: An approach to personality and subjective well-being. J Pers Soc Psychol. 1986;51:1058–68.

5. Little BR. Personal projects: a rationale and method for investigation. Environ Behav. 1983;15:273–309.

6. Palys TS, Little BR. Perceived life satisfaction and the organization of personal project systems. J Pers Soc Psychol. 1983;44:1221–30.

7. Little B. Generative Contexts of Personal Projects Analysis. In: Little BR, Philips SD, Salmela-Aro K, editors. Personal project pursuit: goals, action, and human flourishing. Mahwah, N.J.: Lawrence Erlbaum Associations; 2007. p. 3–49.

8. Locke EA, Latham GP. Building a practically useful theory of goal setting and task motivation: A 35-year odyssey. Am Psychol. 2002;57:705–17.

9. Freund AM. Differentiating and integrating levels of goal representation: a life span perspective. In: Little BR, Philips SD, Salmela-Aro K, editors. Personal project pursuit: goals, action, and human flourishing. Mahwah, N.J.: Lawrence Erlbaum Associations; 2007. p. 247–70.

10. Brunstein JC. Personal Goals and Subjective Well-Being: A Longitudinal Study. J Pers Soc Psychol. 1993;65(5):1061-1070.

11. Carver CS, Scheier MF. Principles of self-regulation: Action and emotion. In: Higgins ET, Sorrentino RM, editors. Handbook of motivation and cognition: Foundations of social behavior. New York, NY: The Guilford Press; 1990. p. 3–52.

12. Klug HJP, Maier GW. Linking goal progress and subjective well-being: a meta-analysis. J Happiness Stud. 2015;16:37–65.

13. Sheldon KM, Kasser T. Goals, Congruence, and Positive Well-Being: New Empirical Support for Humanistic Theories. Nal Humanist Psychol. 2001;41:30–50.

14. Sheldon KM, Kasser T. Pursuing Personal Goals: Skills Enable Progress, but Not all Progress is Beneficial. Pers Soc Psychol Bull. 1998;24:1319–31.

15. Baltes PB. On the incomplete architecture of human ontogeny: Selection, optimization, and compensation as foundation of developmental theory. Am Psychol. 1997;52:366–80.

16. Freund A, Baltes PB. The orchestration of selection, optimization, and compensation: an action-theoretical conceptualization of a theory of developmental regulation. In: Perrig WJ, Grob A, editors. Control of Human Behavior, Mental Processes, and Consciousness : Essays in Honor of the 60th Birthday of August Flammer [Internet]. London: Taylor and Francis; 2000. p. 32–53.

17. Pinquart M, Fröhlich C, Silbereisen RK. Testing models of change in life goals after a cancer diagnosis. J Loss Trauma. 2008;13:330–51.

18. Hullmann SE, Robb SL, Rand KL. Life goals in patients with cancer: a systematic review of the literature: Life goals in patients with cancer. Psychooncology. 2016;25:387–99.

19. Peterman A, Lecci L. Personal projects in health and illness. In: Little BR, Philips SD, Salmela-Aro K, editors. Personal project pursuit: goals, action, and human flourishing. Mahwah, N.J.: Lawrence Erlbaum Associations; 2007. p. 329–53.

20. Sulkers E, Janse M, Brinksma A, Roodbol PF, Kamps WA, Tissing WJE, et al. A longitudinal case–control study on goals in adolescents with cancer. Psychol Health. 2015;30:1075–87.

21. Stefanic N, Caputi P, Iverson DC. Investigating physical symptom burden and personal goal interference in early-stage breast cancer patients. Support Care Cancer. 2014;22:713–20.

22. Wanchai A, Armer JM, Stewart BR. Complementary and Alternative Medicine Use Among Women With Breast Cancer: A Systematic Review. Clin J Oncol Nurs. 2010;14:E45–55.

23. Greenlee H, Balneaves LG, Carlson LE, Cohen M, Deng G, Hershman D, et al. Clinical practice guidelines on the use of integrative therapies as supportive care in patients treated for breast cancer. JNCI Monogr. 2014;2014:346–58.

24. Grant SJ, Hunter J, Seely D, Balneaves LG, Rossi E, Bao T. Integrative Oncology: International Perspectives. Integr Cancer Ther. 2019;18:153473541882326.

25. Verhoef MJ, Mulkins A, Boon H. Integrative health care: how can we determine whether patients benefit? J Altern Complement Med. 2005;11 supplement 1:s-57-s-65.

26. Wallenius MA. Personal project content and stress: relations to subjective health and depressive mood. Soc Indic Res. 2007;81:35–50.

27. Chow AJ, Fergusson D, Seely D, Young S, Pitman A, Ennis J, et al. Personal goals of women recently diagnosed with breast cancer: Protocol for a cohort study. Univ Ott J Med. 2017;7:34–41.

28. von Elm E, Altman DG, Egger M, Pocock SJ, Gøtzsche PC, Vandenbroucke JP, et al. The Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) statement: guidelines for reporting observational studies. J Clin Epidemiol. 2008;61:344–9.

29. Vroman K, Chamberlain K, Warner R. A Personal Projects Analysis: examining adaptation to low back pain. J Health Psychol. 2009;14:696–706.

30. Boersma SN, Maes S, Joekes K, Dusseldorp E. Goal processes in relation to goal attainment: predicting health-related quality of life in myocardial infarction patients. J Health Psychol. 2006;11:927–41.

31. Presseau J, Sniehotta FF, Francis JJ, Gebhardt WA. With a little help from my goals: Integrating intergoal facilitation with the theory of planned behaviour to predict physical activity. Br J Health Psychol. 2010;15:905–19.

32. Presseau J, Boyd E, Francis JJ, Sniehotta FF. Goal conflict and goal facilitation in community-based cardiac rehabilitation: A theory-based interview study. Psychol Health Med. 2015;20:227–38.

33. Little B, Gee T. The methodology of Personal Projects Analysis: four modules and a funnel. In: Little BR, Philips SD, Salmela-Aro K, editors. Personal project pursuit: goals, action, and human flourishing. Mahwah, N.J.: Lawrence Erlbaum Associations; 2007. p. 51–93.

34. Ivers NM, Grimshaw JM, Jamtvedt G et al. Growing Literature, Stagnant Science? Systematic Review, Meta-Regression and Cumulative Analysis of Audit and Feedback Interventions in Health Care. J Gen Intern Med. 2014 Nov; 29(11): 1534–1541.

35. Wiese B. Successful Pursuit of Personal Goals and Subjective Well-Being. In: Little BR, Philips SD, Salmela-Aro K, editors. Personal project pursuit: goals, action, and human flourishing. Mahwah, N.J.: Lawrence Erlbaum Associations; 2007. p. 301–25.

36. Hsieh H-F, Shannon SE. Three Approaches to Qualitative Content Analysis. Qual Health Res. 2005;15:1277–88.

37. Braun V, Clarke V. Using thematic analysis in psychology. Qual Res Psychol. 2006;3:77–101.

38. Paul A. What Are the Personal Goals of Women with Breast Cancer and What Hinders Goal Achievement? (S736). J Pain Symptom Manage. 2017;53:429.

39. Pama MR, Janse M, Sprangers MAG, Fleer J, Ranchor AV. Reducing discrepancies of personal goals in the context of cancer: A longitudinal study on the relation with well-being, psychological characteristics, and goal progress. Br J Health Psychol. 2018;23:128–47.

40. Janse M, Ranchor AV, Smink A, Sprangers MAG, Fleer J. Changes in cancer patients' personal goals in the first 6 months after diagnosis: the role of illness variables. Support Care Cancer. 2015;23:1893–900.

41. Elliot AJ, Sheldon KM. Avoidance personal goals and the personality–illness relationship. J Pers Soc Psychol. 1998;75:1282–99.

42. Klinger E, Cox WM. Chapter 1: Motivation and the Theory of Current Concerns. In: Handbook of Motivational Counseling. Chichester: John Wiley & Sons, Ltd.; 2004. p. 3–27.

43. Emmons RA. Personal goals, life meaning, and virtue: Wellsprings of a positive life. In: Keyes CLM, Haidt J, editors. Flourishing: Positive psychology and the life well-lived. Washington: American Psychological Association; 2003. p. 105–28. doi:10.1037/10594-005.

44. Frenkel M, Cohen L, Peterson N, Palmer JL, Swint K, Bruera E. Integrative medicine consultation service in a comprehensive cancer center: findings and outcomes. Integr Cancer Ther. 2010;9:276–83.

45. Verhoef MJ. Reasons for and Characteristics Associated With Complementary and Alternative Medicine Use Among Adult Cancer Patients: A Systematic Review. Integr Cancer Ther. 2005;4:274–86.

46. Stefanic N, Iverson DC, Caputi P, Lane L. Examining the influence of personal goal interference and attainability on psychological distress in non-metastatic breast cancer patients. Eur J Cancer Care (Engl). 2016. doi:10.1111/ecc.12494.

47. Baltes PB, Baltes MM. Psychological perspectives on successful aging: The model of selective optimization with compensation. In: Baltes PB, Baltes MM, editors. Successful aging. Cambridge: Cambridge University Press; 1990. p. 1–34.

48. Mens MG, Scheier MF. The Benefits of Goal Adjustment Capacities for Well-Being Among Women With Breast Cancer: Potential Mechanisms of Action: Goal Adjustment, Well-Being, and Breast Cancer. J Pers. 2016;84:777–88.

49. Thompson E, Stanton AL, Bower JE. Situational and Dispositional Goal Adjustment in the Context of Metastatic Cancer. 2013;81:441–51.

50. Lam WWT, Yeo W, Suen J, Ho WM, Tsang J, Soong I, et al. Goal adjustment influence on psychological well-being following advanced breast cancer diagnosis: Goal adjustment and psychological well-being. Psychooncology. 2016;25:58–65.

51. Wrosch C, Scheier MF, Miller GE, Schulz R, Carver CS. Adaptive self-regulation of unattainable goals: goal disengagement, goal reengagement, and subjective well-being. Pers Soc Psychol Bull. 2003;29:1494–508.

52. Riediger M. Interference and facilitation among personal goals: age and associations with well-being and behavior. In: Little BR, Philips SD, Salmela-Aro K, editors. Personal project pursuit: goals, action, and human flourishing. Mahwah, N.J.: Lawrence Erlbaum Associations; 2007. p. 119–43.

53. Stefanic N, Caputi P, Lane L, Iverson DC. Exploring the nature of situational goal-based coping in early-stage breast cancer patients: A contextual approach. Eur J Oncol Nurs. 2015;19:604–11.

54. Janse M, Sprangers MAG, Ranchor AV, Fleer J. Long-term effects of goal disturbance and adjustment on well-being in cancer patients. Qual Life Res. 2016;25:1017–27.

55. Schroevers M, Kraaij V, Garnefski N. How do cancer patients manage unattainable personal goals and regulate their emotions? Br J Health Psychol. 2008;13:551–62

56. Sullivan-Singh SJ, Stanton AL, Low CA. Living with limited time: Socioemotional selectivity theory in the context of health adversity. J Pers Soc Psychol. 2015;108:900–16.

57. Krahmer. Thinking About Thinking Aloud: A Comparison of Two Verbal Protocols for Usability Testing. IEEE Trans Prof Commun. 2004;47:105–17.

58. Boren T, Ramey J. Thinking aloud: reconciling theory and practice. IEEE Trans Prof Commun. 2000;43:261–78.

59. LaVeist TA. Beyond dummy variables and sample selection: what health services researchers ought to know about race as a variable. Health Serv Res. 1994;29:1–16.

60. Corbie-Smith G, Henderson G, Blumenthal C, Dorrance J, Estroff S. Conceptualizing race in research. J Natl Med Assoc. 2008;100:1235–43.

61. Canadian Cancer Society. Complementary Therapies: A Guide for People with Cancer. 2014. https://www.cancer.ca/~/media/cancer.ca/CW/publications/Complementary%20therapies/Complementary-therapies-EN.pdf. Accessed 21 Apr 2018.

Appendix 1 - Amendments to the Protocol

EFFECTIVE DATE	SECTION	ORIGINAL LANGUAGE	AMENDED LANGUAGE	RATIONALE
April 21, 2017	Methods – timing of data collection	Data was going to be collected from participants in 3 rounds of Head Start.	Data will be collected from participants in two rounds of Head Start.	Due to a longer-than-anticipated ethics review process and time availability of the lead author, this research project was amended.
April 21, 2017	Methods – data collection methods: goal content review	At T2, participants will be shown their T1 questionnaires and asked to annotate any changes they wish to make to their lists of six most important personal projects.	At T2, participants will be shown the most important goals that they identified on their T1 questionnaires.	This amendment is expected to make it easier for participants by reducing the number of pages in the T2 and T3 questionnaires by listing the goals instead of providing a copy of the T1 questionnaire.
April 21, 2017	Methods - data collection methods: Feasibility testing of data collection tools	A two-part feasibility testing process is described.	Instead of the proposed feasibility testing, four colleagues will be engaged in questionnaire development. Two colleagues will provide feedback on the clarity, language and format of the questionnaire. Two colleagues will be engaged to observe completion of the questionnaires, and provide feedback on the clarity, language and format of the questionnaire.	Due to a longer-than-anticipated ethics review process and time availability of the lead author, this research project was amended to enable us to begin data collection with Head Start participants participating in the May 2017 round of the program.
May 4, 2017	Methods – additional variables; Table 2	We identify race and marital status as two demographic variables for which we will collect data.	Race will be removed as a study variable. Marital status will be replaced with current living situation (with whom a participant lives).	During questionnaire development, it was decided that race was not a variable that we expected to affect the primary study measures, barriers and facilitators to goal pursuit. It was also decided that whom a person lives with addresses questions of social support more than marital status.
May 4, 2017	Methods – participants: consent	Two copies of the informed consent form were to be signed; one copy to be kept by the participant and the other by the researcher.	One copy of the consent form will be signed and kept by the researcher; a copy of the signed form will be made immediately following signing and provided to the participant	This Amendment is consistent with the language of the Informed Consent Form approved by the Ottawa Hospital Science Network's Research Ethics Board (OHSN-REB), which states that the participant "will be given a copy of this signed

				Participant Informed Consent Form."
July 25, 2017	Methods - Timing of data collection (p6)	T3 is defined as 2 – 3 months after T2.	T3 is defined as 2 – 3 months after the end of Head Start	The definition of T3 that appears in this section differs from the definition provided in Table 1, where T3 is defined as 2 – 3 months after the end of Head Start. This Amendment is made for consistency.
July 27, 2017	Analytic methods – qualitative variables	None	If a participant responds with two goals in the same line of the questionnaire, the two goals will be treated as the same in content analysis. If the two goals are notably different, the first one will be analyzed.	Two goals can be treated as the same as analysis if they are similar, but should not be analyzed together if they are different.
August 3, 2017	Methods – data collection methods: barriers and facilitators to goal pursuit	Goals will be selected to represent as large a range of goal pursuit scores on the T3 questionnaire, and to represent goals whose pursuit scores changed by +/- 2 points between the T2 and T3 questionnaires.	All participants will be asked about barriers and facilitators to the same types of goals.	Asking all participants about the same type of goals provides consistency in analysis across participants.
August 24, 2017	Methods – primary analysis	Barriers and facilitators to goal pursuit will be analyzed using directed content analysis. The development of themes will be guided by the Theoretical Domains Framework (TDF).	Barriers and facilitators to goal pursuit will be analyzed using inductive analysis.	Because of the small sample size, and to maintain consistency with Braun and Clarke's process guidelines for qualitative research,[31] we decided that an inductive approach would be better suited to identifying barriers and facilitators.
February 2, 2018	Methods – Additional variables, qualitative analyses	Data on important Head Start program elements will be collected from exposed participants only, using the Measure Yourself Concerns and Well-Being (MYCAW) questionnaire[23]. …Important aspects of Head Start from the MYCAW will be analyzed using the same thematic approach.	Only data from the follow-up MYCAW form was collected for this study. Proper analysis additionally required specific data from the first MYCAW form.	As this data was not central to our objectives, we chose to omit this analysis.

Appendix 2 – Recruitment Script

I'd like to tell you about a study that will be taking place soon. A Master's student at the University of Ottawa, Andrea Chow, is doing a research study to learn more about how women who have recently received a diagnosis of breast cancer think and feel about personal goals, and the things that help or hinder a woman to pursue her goals. She's interested in patient-centered care and integrative cancer treatment, and how a better understanding of women's goals could help improve the response to women's priorities during cancer treatment and care. The OICC supports research that aims to improve the practice of integrative oncology in Canada. This is not a study that the OICC is conducting, but Andrea is doing her study with our support and collaboration. We know research can be time-consuming, but it's so helpful to continue to learn more about what it's like to have a cancer diagnosis and what's important to women at this time. Andrea's hoping to meet with women who are participating in the Head Start program, or on the waiting list. She's given us some information that I can share with you, that tells a bit more about what the study is about, and what would be asked of you if you participate. Your participation in Head Start or your current and future care at the OICC will not be affected in any way by your decision about participating in the study. Study participation is completely voluntary.

Do you think you might be interested in participating in this research study or want to learn more about it? (*Three options):*

1. *If yes,*

Andrea will be delighted to hear that. So the next thing that will happen is - I will e-mail you a copy of the letter from Andrea, as well as the consent form. You don't have to sign the consent form now – Andrea would like to meet with you to go over the form and explain what's involved before you sign the form. She just wanted you to have it to look over while making your decision.

When I email you, I'd like to copy Andrea on that email so she can follow up with you directly. You still can choose not to participate in the study. Are you comfortable with Andrea being copied on the e-mail? It means that she will then have your name and email address and will contact you directly. (*Wait for verbal consent).*

⇒ *If consent* – OK, great. I'll copy Andrea on the email I send you.

⇒ *If does not consent* – That's OK. Andrea's contact details will be on the information sheet I send you. I won't copy her on the message, but please contact her to let her know if you would like to participate in the study.

2. *If maybe or unsure,*

That's OK. I can e-mail you a letter of information and a consent form about the study that Andrea has provided me. You don't have to sign the consent form – but it has more information about the study that you can use to make your decision. If you decide to participate, Andrea will meet with you to go over the form and explain the process before you sign the form.

When I email you, I'd like to copy Andrea on that email so she can follow up with you directly. You still can choose not to participate in the study. Are you comfortable with Andrea having your email address and contacting you in the next few days? (*Wait for verbal consent).*

⇒ *If consent* – OK, great. I'll copy Andrea on the email I send you.

⇒ *If does not consent* – That's OK. Andrea's contact details will be on the letter of information I send you. I won't copy her on the message, but please contact her to let her know if you would like to participate in the study.

3. *If No:*

That's absolutely fine. Thank you for considering it.

Version Date December 21, 2016

Appendix 3 – Letter of Information

Hello,

My name is Andrea Chow, and I am a student in the Master's degree program in Epidemiology at the University of Ottawa. For my thesis, I am doing a research study to learn more about the life goals of women while dealing with breast cancer. I am writing to you because you are enrolled in an upcoming Head Start workshop and you shared with Anne, Rabia or Sarah at the OICC that you may be open to taking part in my research study. Thank you for this.

I am interested in learning about what women's goals in their daily lives are, how they feel and think about their goals, and the things that help them to pursue their goals, or that interfered with the pursuit of goals. There are places that practice integrative oncology (combining conventional cancer treatment such as chemotherapy with complementary therapies such as massage or meditation), like the Ottawa Integrative Cancer Centre (the OICC), and their purpose is to provide patient-centered care. But not much research has been done on life goals among people living with cancer, not just goals for your health, but also goals for family, work, community, and leisure. We hope that learning more about goals can help us learn more about the priorities of women while they are dealing with cancer, so that patient-centered care can improve support to women to pursue their goals.

Eligibility
I am looking for volunteers to take part in this research study who:

- Are enrolled in or on the waiting list for Head Start
- Are aged 18 years or older
- Are female
- Have received a breast cancer diagnosis within the past five months
- Are experiencing their first cancer diagnosis
- Can speak, write and understand English well

Volunteering
Taking part in research is voluntary, and you may choose not to participate. Your decision will have no effect on whether you participate in Head Start or on your current and future care or services you receive at the OICC.

What comes next?
During your recent conversation with Anne, Rabia or Sarah at the OICC, she asked you for consent for me to contact you. If you said yes, I will be doing that in the next few days. If you have changed your mind and do not want me to contact you, you can inform me by e-mail at [email redacted for thesis submission]. I will respect your wishes.

If you chose not to provide consent for me to contact you, and you would like to take part in this study, please send me an e-mail at [email redacted for thesis submission] and let me know how I should contact you (phone or e-mail).

If you want to take part in the study, I will set up a time to meet with you over the next week or so, so we can discuss the study and what is expected more fully in person. We'll find a time and place that's good for you. Also attached to this e-mail is a consent form which explains the research study in detail, including what is involved in taking part in the study. We will go over the consent form in our meeting, but feel free to read this in advance. We will discuss any questions you have in our meeting.

Ethics clearance
This research study has been approved by the Ottawa Health Science Network Research Ethics Board.

Please do not hesitate to call me if you have any questions as you read over this letter. My phone number is [redacted for thesis submission]. I am happy to answer your questions. You may also ask questions of Dr. Dugald Seely at the OICC, or of my research supervisors, Dr. Dean Fergusson or Dr. Justin Presseau. Contact information for all parties appears at the end of this letter.

Thank you very much for your time.

Sincerely,

Andrea Chow
M. Sc. candidate, School of Epidemiology, Public Health and Preventive Medicine
University of Ottawa
[contact information redacted for thesis submission]

Contact information

[redacted for thesis submission]

Version Date December 21, 2016

Appendix 4 - Development of data collection tools

To develop the data collection tools, we elicited feedback from colleagues with a range of expertise. Authors provided expertise on various aspects, including questionnaire and interview content and development, dealing with breast cancer, and the Head Start intervention. Feedback was used to refine the questionnaires in a reiterative manner. For example, multiple people who provided input emphasized that women recently diagnosed with breast cancer are preoccupied with coping with their diagnosis and that being asked to identify their goals may feel like an additional, unwanted task. We therefore took suggestions to specify on the T1 questionnaire that participants did not need to identify any goals at all if they did not have any, and that "there are no right or wrong answers." To get perspectives that were more similar to those of potential participants, two women within AC's personal networks (F1, F2), both over the age of 50, then completed the T1 and T2 questionnaires in AC's presence in order to determine the length of time required to complete the questionnaires. Both individuals also provided feedback on questionnaire content, format and language. F2 was also asked to "speak aloud" as she completed the questionnaires, to obtain real-time information on question interpretation.[57,58] Another individual within AC's personal networks who is a breast cancer survivor (F3) reviewed the content and language of the T1 and T2 questionnaires. F2 and F3 also reviewed the instructions for goal pursuit ratings in the T3 questionnaire for clarity. The rest of the T3 questionnaire was not reviewed, as it was the same as the T2 questionnaire. We asked the women to provide general feedback on the questionnaires, as well as specific feedback on their lengths, readability, and clarity.

Pilot testing: Several revisions were made to the questionnaires after consultation with these three women. The format and instructions were clarified and simplified as much as possible. We had originally used the term "personal projects" to describe personal goals, the term used in the Personal Projects Analysis, which we used to elicit and assess women's goals in this study.[5] The women felt that the term "personal goals" was more familiar, and easier to understand. They also felt that "personal projects" had a negative, task-related connotation. We subsequently changed all references from "personal projects" to "personal goals".

It took F1 22 minutes, and F2 27 minutes while "speaking aloud," to complete the T1 questionnaire. This length was within the range expected when first tested by the authors and

found to be acceptable to both women. We also made changes to two demographic variables, race and marital status.

Race: This was originally included to help describe the study population as a whole. Race, however, is a social construct and should be treated carefully in health research.[60,61] Categorizations that we found in the literature were problematic (i.e. not mutually exclusive categories, conflating race and ethnicity). An expert in social epidemiology suggested collecting the data as an open-ended variable, asking participants for racial self-identification. During completion of the T1 questionnaire, neither woman responded to our question, "In terms of racial identity, how do you self-identify?" in a way that provided us with information on their race. The usefulness of this variable was questioned by one woman. Race was not hypothesized to be related to the other study variables in a way that was important to our study objectives, so we decided to remove the variable from the study all together.

Marital status: In discussions with the women, we were able to clarify that we were actually interested in a participant's social supports. Marital status, a particular legal standing, was perhaps less important the presence of strong, close relationships in a participant's life. In order to reflect this, we decided to change the variable collected from marital status to "current living situation," which captures the people with whom the participant lives.

To pilot the interview guide, AC conducted mock interviews with three people in her personal networks following the interview guide. The length, questions, and language of the guide was refined with each iteration. During this process, the number of questions was reduced to be manageable within the study's proposed 45-minute interview timeframe. To ensure consistency, we decided to ask each participant about her most pursued goal and her least pursued goal.

Appendix 5 – Definitions of Added and Modified Goals

Added goals were entered into the space for new goals and were judged to be different in content from any other goal on the participant's list, representing a different activity, project, or target than any other goal

Modified goals met one of the following criteria:

- Changes made to an existing goal by crossing out some of the words in the original goal and adding new, different words
- Goal entered into a space for new goals but the wording of the goal was only changed in a minor way, for example, changing the frequency, timing or location of a goal

Appendix 6 – Data Collection Tools

QUESTIONNAIRE #1

Personal goals of women living with breast cancer

Please write down your alias or code name: _____

Please enter today's date (YY/MM/DD): _____/_____/_____

Your personal goals

Thank you for volunteering to take part in this study. We have asked you to take part because we are interested in learning more about your goals and priorities while you also deal with a recent breast cancer diagnosis.

Many things in your life may be or feel different than before your diagnosis. We are interested in understanding you and your experiences at this time, based on the things that you plan to do that are important to you. We call these your "**personal goals**". We all have personal goals, from the grandiose to the mundane. Our goals define how we spend our time and energy. Goals may be related to any aspect of your daily life, from the very common things that most people do, to the very specific things that perhaps only you do! They can be related to your health, work, home, and community, among others. Please think of goals in this broad way and in relation to the next 3 to 4 months.

The personal goals that we're interested in are the **goals that you're planning on undertaking over the next 3-4 months**. They may be new goals and/or ongoing ones that you have been pursuing for a while. We are also interested in finding out what you think and feel about these personal goals.

Some examples of personal goals

Personal goals may be focused on:

- Something you want to achieve — "*Increase my exercise to 3 times a week"*
- Something new — "*Approach life with the happiness I feel today"*
- Something you have been doing for years — "*Walk my dog every morning*"
- Something you want to avoid — "*Stay away from sugar*"
- Something you want to do — *"Enjoying a night out with friends"*
- Something you feel you ought to do — "*Call my brother more often*"

Please turn the page to start.

What are your personal goals?

To start, please take 10 minutes and write down, *in your own words,* **up to 12 personal goals that you want to pursue in your daily life over the next 3 – 4 months**.

What if I can't think of 12 personal goals? Although we ask for 12 at the most, you can list fewer if you want – it's OK to list one or two if those are the goals that define what you will be up to over the next 4 months.

What if I can't think of ANY goals? That is OK. It's helpful for us to know that. Please don't feel any pressure to write down goals just because there is space. **Skip the next few pages and turn to page 7.**

Goal # Goal Description (in your own words – there are no right or wrong answers!)

1 _____

2 _____

3 _____

4 _____

5 _____

6 _____

7 _____

8 _____

9 _____

10 _____

11 _____

12 _____

NEXT: From your list, please **circle 6 goals** that are the most important to you. If you listed *exactly* or *fewer than* 6 goals, please circle all 6.

How do you think and feel about your personal goals?

On the following page, we would like you to consider how you think and feel about your goals.

On page 6 is a list of the dimensions and a more detailed explanation of what each one means. Please **detach the list for easy reference** and refer to it as needed while you rate your goals.

Follow the instructions at the top of the next page (page 5).

INSTRUCTIONS:

Step 1: Copy your 6 most important goals from your list on to the table in the column on the left.

Step 2: Please rate from 0 to 10 how you think and feel about each of your 6 most important goals in the dimensions along the top. Please use the definitions of each dimension on page 6. If you feel a dimension is **not relevant** to one of your goals, you may put an "X" in the space instead of a number, but **please try to rate each goal on all dimensions if possible**.

		What do you think about what you will be doing?								How do you feel about what you will be doing?				
	Personal goals	Challenge	Likelihood of Success	Autonomy	Intention	Attention	Support	Time adequacy	Self-identity	Hopeful	Scared	Sad	Happy	Stressed
1														
2														
3														
4														
5														
6														

Goal Dimension Definitions

1. Challenge

How challenging do you think this goal will be?
(Use **10** if you think it will be extremely challenging, perhaps more than you can handle, and **0** if you think it will be not at all challenging – almost boring.)

2. Likelihood of Success

How successful do you believe this goal will be?
(Use **10** if you expect the goal to be entirely successful, and **0** if you think the goal will turn out to be a total failure.)

3. Autonomy

How much is this goal one which you feel you will pursue autonomously, that is, you will be engaged of your own free will in the goal, not because anyone else wants you to do it.
(Use **10** if you will be engaged in this goal entirely of your own free will, and **0** if this goal is one that you feel totally obliged to complete because of or for someone else.)

4. Intention

How much do you intend to pursue this goal, that is, how much do you want to pursue this goal?
(Use **10** if you fully intend to pursue the goal, and **0** if you do not intend to pursue it at all.)

5. Attention

How much attention do you think you can give to this goal?
(Use **10** for a goal that you plan to give your full attention, and **0** for one that you plan to give no attention at all.)

6. Support

To what extent do you feel this goal will be supported by other people? Support may come in different forms, e.g. emotional (encouragement, approval), financial (money, material possessions) or practical (active assistance).
(Use **10** if you feel other people will give full support for the goal, and **0** if there will be no support at all.)

7. Time Adequacy

Do you have enough time to spend working on this goal?
(Use **10** if you feel the amount of time you have will be perfectly adequate, and **0** if you feel that the amount of time you will have to spend working on the goal will not be at all adequate.)

8. Self-Identity

All of us have things we do that we feel are typical or truly expressive of us. These things can be thought of as our "trade marks". For example, some people engage in sports every chance they get, others prefer to read, others prefer to socialize. **Think of what your own personal "trade marks" are, and then rate this goal on the extent to which it is typical of you.**
(Use **10** if a goal is very typical of you, and **0** if it is not typical at all.)

9 – 13. Feelings (hopeful, scared, sad, happy, stressed)

To what extent do you feel each emotion while thinking about doing each goal?
(Use **10** if you experience the emotion very strongly, and **0** if you don't feel it at all.)

If you did not list any goals on page 2, please complete this page.

Otherwise, please go ahead to page 8.

Could you tell us more about why you did not list any personal goals (for example, "I've got too much on my mind right now", "I didn't understand the word 'goal', I don't want to focus on goals")? **All feelings are natural and normal, and all answers are valid.**

A little more about you

We hope to learn more about women who are interested in integrative oncology. All of the information you share with us will be reported for the group as a whole, and will not be used to identify you.

1. What is your age, as of today?

_____ years old

2. What is your current living situation? *Please select one.*

- ☐ Living alone (with or without pets)
- ☐ Living with one or more non-family members (you can define who you think of as family
- ☐ Living with one or more family members you can define who you think of as family)
- ☐ I prefer not to say

3. What is the highest level of education that you have completed? *Please select one.*

- ☐ Some high school
- ☐ High school diploma
- ☐ Some post-secondary school (for example, college, trade school, or university)
- ☐ Post-secondary certificate or diploma
- ☐ Undergraduate university degree (for example, B.A., B. Sc.)
- ☐ Post-graduate university degree (for example, M.A., Ph.D., M.D.)
- ☐ I don't know
- ☐ I prefer not to say

4. What was your *household* income, before taxes, in 2016? *Please select one.*

- ☐ Less than $30,000
- ☐ Between $30,000 and $50,000
- ☐ Between $50,001 and $90,000
- ☐ Between $90,001 and $150,000
- ☐ $150,001 or above
- ☐ I don't know
- ☐ I prefer not to say

5. What was the date of your breast cancer diagnosis? If you don't remember the exact date, enter the year and month.

(YY/MM/DD) _____/_____/_____

6. What is your breast cancer stage (if known):

_____

Thank you!

This is the end of the first of three questionnaires that you will be asked to complete for this study. Thank you very much for sharing this information about your personal goals and how you think and feel about them. It is truly appreciated.

As always, please don't hesitate to ask if you have questions at any time.

Thank you again,

Andrea

QUESTIONNAIRE #2

Personal goals of women living with breast cancer

Please write down your alias or code name: _____

Please enter today's date (YY/MM/DD): _____/_____/_____

Introduction

A few weeks ago, you kindly told us about your personal goals, because we are interested in learning more about your goals and priorities while you also deal with a recent breast cancer diagnosis. Today, we are going to re-visit those personal goals (*the kinds of activities and concerns you have*) that you identified as important to you. We have a few questions about how your personal goals are going, whether you have different goals today, and how you feel and think about the goals you have now.

Thank you for taking the time to share this information. This questionnaire should take about 15 to 25 minutes to complete.

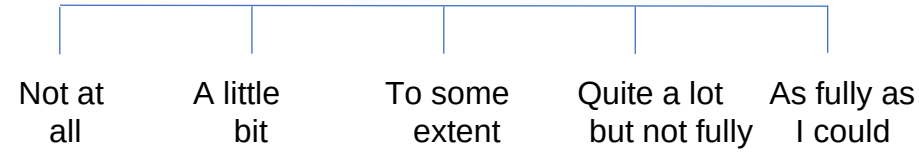
Please turn the page to start.

Pursuit of your personal goals

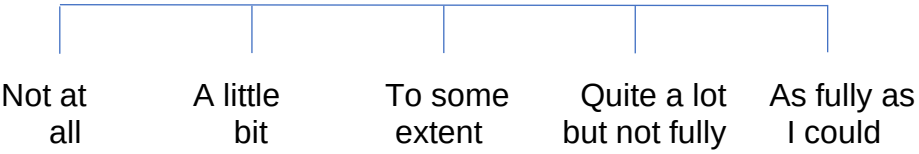
We have copied the 6 (or fewer) most important personal goals that you chose 1 month ago. If you listed 0 important personal goals, please turn to page 5.

As best as you can recall, how much did you feel you pursued each goal over the last 30 days? Please circle the answer that best reflects how you feel.

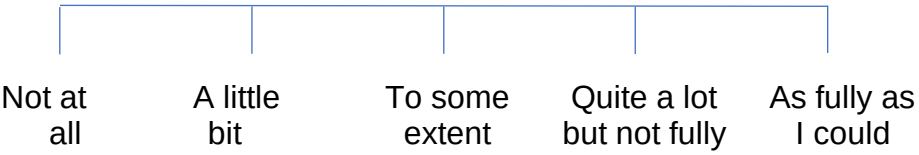
Goal #1: _ *The goal will be filled in in advance by the researcher*__



Goal #2: _ *The goal will be filled in in advance by the researcher*__

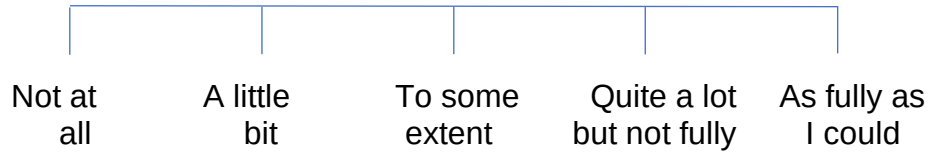


Goal #3: _ *The goal will be filled in in advance by the researcher*__

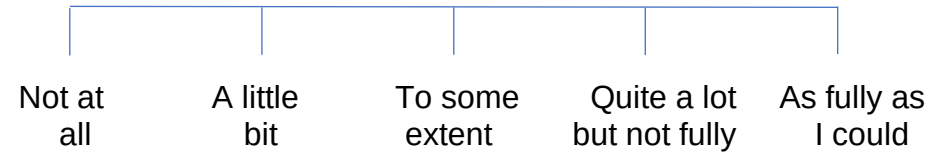


Goal #4: _ *The goal will be filled in in advance by the researcher*__

Goal #5: _ *The goal will be filled in in advance by the researcher*__



Goal #6: _ *The goal will be filled in in advance by the researcher*___



Your personal goals

We are interested in what your most important personal goals are today, and whether they have changed since the last time we met.

To refresh your memory on what we mean when we talk about personal goals, we are interested in understanding you and your experiences as you deal with a recent diagnosis of breast cancer, based on the things that you plan to do that are important to you. We call these your "**personal goals**". We all have personal goals, from the ordinary to the extraordinary. Our goals define how we spend our time and energy.

The personal goals that we're interested in today are **the goals that you're planning on undertaking over the next 2 – 3 months**.

Goals may be related to **any aspect of your daily life**, from the very common things that most people do, to the very specific things that perhaps only you do! They can be related to your health, work, home, and community, among others. Please think of goals in this broad way and in relation to the next 2 to 3 months.

Some examples of personal goals

Personal goals may be focussed on:

- Something you want to achieve "*Increase my exercise to 3 times a week"*
- Something new "*Approach life with the happiness I feel today"*
- Something you have been doing for years "*Walk my dog every morning*"
- Something you want to avoid "*Stay away from sugar*"
- Something you want to do *"Enjoying a night out with friends"*
- Something you feel you ought to do "*Call my brother more often*"

We are also interested in finding out what you think and how you feel about these personal goals and activities, how challenging or stressful they are, and so on.

Please turn the page to start.

What are your most important personal goals?

How do you think and feel about your goals?

What are your 6 most important personal goals over the next 2 – 3 months?

On the table on the next page, in the column on the left, is your list of important personal goals that you identified the last time we met. **Please review the list and think about whether it still reflects your most important goals, or whether any have changed.**

1. If you wish to **remove a goal**, draw a line through it (for example, my goal).

2. Underneath each goal you will find space to **add a new important personal goal** or **modify your goal**.

3. It's OK to have fewer than 6 goals if that's how many you have. If you feel that you have no important personal goals over the next 2 – 3 months, skip the next few pages and turn to **page 9.**

How do you think and feel about your goals?

1. On page 8 is a list of these dimensions and a more detailed explanation of what each one means. Please **detach the list for easy reference** and refer to it as needed while you rate your goals.

2. Please turn to the next page (page 7) and **follow the instructions** at the top of the page.

INSTRUCTIONS

STEP 1: Update your list of important goals. Scratch out any goals that are no longer important and add any new goals that you plan to do in the column on the left.

STEP 2: Please rate from 0 to 10 how you think and feel about each goal in the dimensions along the top. Please use the definitions on page 8. *Do not complete ratings for goals from your original list that you have scratched out.* If you feel a dimension is **not relevant** to one of your goals, you may put an "X" in the space instead of a number, but **please try to rate each goal on all dimensions if possible**.

		What do you think about what you will be doing?								How do you feel about what you will be doing?				
	Goals	**Challenge**	**Likelihood of Success**	**Autonomy**	**Intention**	**Attention**	**Support**	**Time adequacy**	**Self-identity**	**Hopeful**	**Scared**	**Sad**	**Happy**	**Stressed**
1	Goal will be filled in by researcher in advance Or new goal: _____													
2	Goal will be filled in by researcher in advance Or new: _____													
3	Goal will be filled in by researcher in advance Or new: _____													
4	Goal will be filled in by researcher in advance Or new: _____													
5	Goal will be filled in by researcher in advance Or new: _____													
6	Goal will be filled in by researcher in advance Or new: _____													

Goal Dimension Definitions

1. Challenge

How challenging do you think this goal will be?
(Use **10** if you think it will be extremely challenging, perhaps more than you can handle, and **0** if you think it will be not at all challenging – almost boring.)

2. Likelihood of Success

How successful do you believe this goal will be?
(Use **10** if you expect the goal to be entirely successful, and **0** if you think the goal will turn out to be a total failure.)

3. Autonomy

How much is this goal one which you feel you will pursue autonomously, that is, you will be engaged of your own free will in the goal, not because anyone else wants you to do it.
(Use **10** if you will be engaged in this goal entirely of your own free will, and **0** if this goal is one that you feel totally obliged to complete because of or for someone else.)

4. Intention

How much do you intend to pursue this goal, that is, how much do you want to pursue this goal?
(Use **10** if you fully intend to pursue the goal, and **0** if you do not intend to pursue it at all.)

5. Attention

How much attention do you think you can give to this goal?
(Use **10** for a goal that you plan to give your full attention, and **0** for one that you plan to give no attention at all.)

6. Support

To what extent do you feel this goal will be supported by other people? Support may come in different forms, e.g. emotional (encouragement, approval), financial (money, material possessions) or practical (active assistance).
(Use **10** if you feel other people will give full support for the goal, and **0** if there will be no support at all.)

7. Time Adequacy

Do you have enough time to spend working on this goal?
(Use **10** if you feel the amount of time you have will be perfectly adequate, and **0** if you feel that the amount of time you will have to spend working on the goal will not be at all adequate.)

8. Self-Identity

All of us have things we do that we feel are typical or truly expressive of us. These things can be thought of as our "trade marks". For example, some people engage in sports every chance they get, others prefer to read, others prefer to socialize. **Think of what your own personal "trade marks" are, and then rate this goal on the extent to which it is typical of you.**
(Use **10** if a goal is very typical of you, and **0** if it is not typical at all.)

9 – 13. Feelings (hopeful, scared, happy, sad, stressed)

To what extent do you feel each emotion while thinking about doing each goal?
(Use **10** if you experience the emotion very strongly, and **0** if you don't feel it at all.)

A little more about your treatment

We hope to learn more about women who are interested in integrative oncology. All of the information you share with us will be combined with everyone else in the study, so that it will not be used to identify you specifically.

1. **Are you currently receiving treatment for breast cancer, besides any hormone therapy? (E.g. radiation, chemotherapy, surgery, etc.)**

   ☐ Yes

   ☐ No

   ☐ I prefer not to answer

2. **Are you currently receiving any complementary therapies (at the Ottawa Integrative Cancer Centre, or at other centres)?**

   ☐ Yes

   ☐ No

   ☐ I prefer not to answer

Thank you!

This is the end of the second of three questionnaires that you will be asked to complete for this study. Thank you very much for sharing this information about your personal goals and how you think and feel about them. It is truly appreciated.

As always, please don't hesitate to ask if you have questions at any time.

Thank you again,

Andrea

QUESTIONNAIRE #3

Personal goals of women living with breast cancer

Please write down your alias or code name: _____

Please enter today's date (YY/MM/DD): _____/_____/_____

Introduction

A few months ago, you kindly told us about your personal goals, because we are interested in learning more about your goals and priorities while you also deal with a recent breast cancer diagnosis. Today, we are going to re-visit those personal goals (*the kinds of activities and concerns you have*) that you identified as important to you. We have a few questions about how your personal goals are going, whether you have different goals today, and how you feel and think about the goals you have now.

Thank you for taking the time to share this information. This questionnaire should take about 15 to 25 minutes to complete.

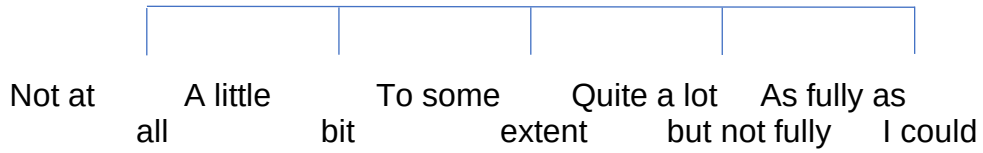
Please turn the page to start.

Pursuit of your personal goals

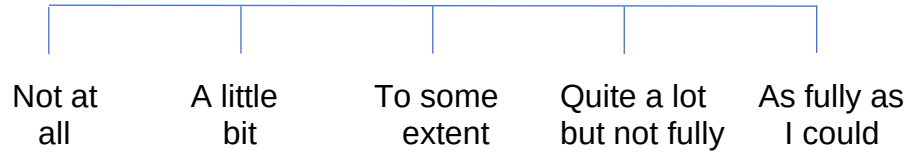
We have copied the 6 (or fewer) most important personal goals that you chose on the first questionnaire <3-4> months ago, as well as any new personal goals that you chose on the second questionnaire <2-3> months ago. If you did not identify ANY important personal goals on the first or second questionnaire, please turn to page 6.

As best as you can recall, how much did you feel you pursued each goal over the last <2 – 3> months? Please circle the answer that best reflects how you feel.

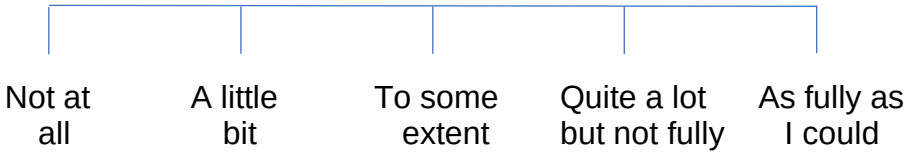
Goal #1: _ *The goal will be filled in in advance by the researcher*__



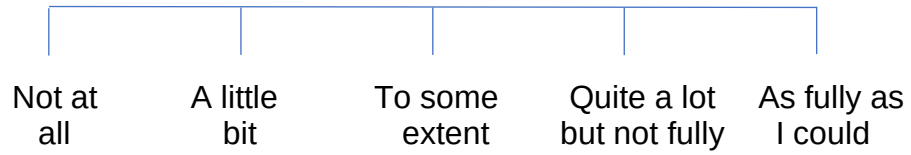
Goal #2: _ *The goal will be filled in in advance by the researcher*__



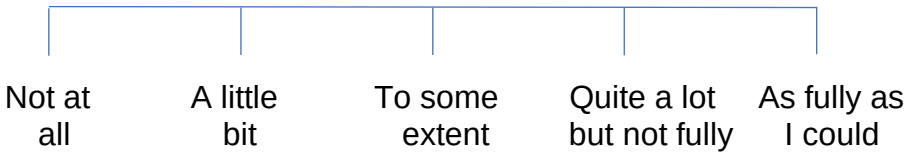
Goal #3: _ *The goal will be filled in in advance by the researcher*__



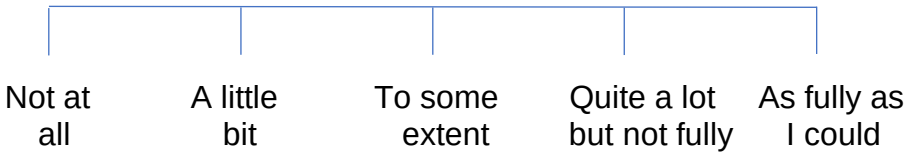
Goal #4: _ *The goal will be filled in in advance by the researcher*__



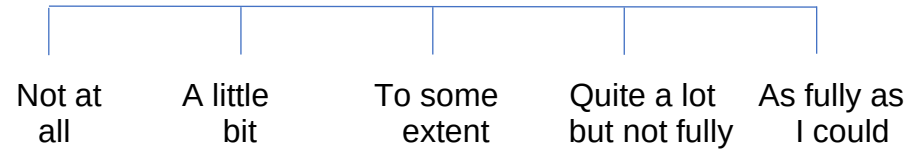
Goal #5: _ *The goal will be filled in in advance by the researcher*__



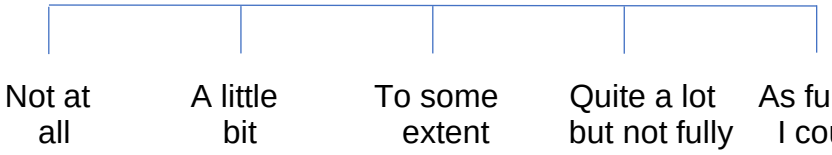
Goal #6: _ *The goal will be filled in in advance by the researcher*___



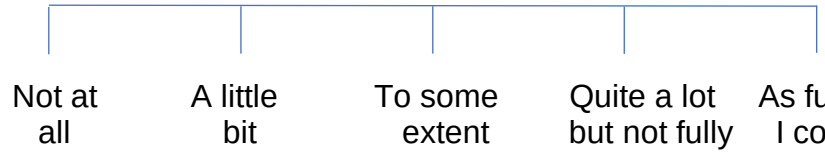
Goal #7 (if applicable): _ *The goal will be filled in in advance by the researcher*__



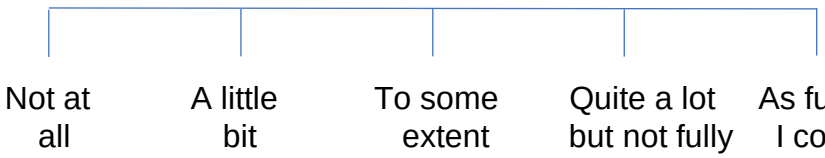
Goal #8 (if applicable): _ *The goal will be filled in in advance by the researcher*__



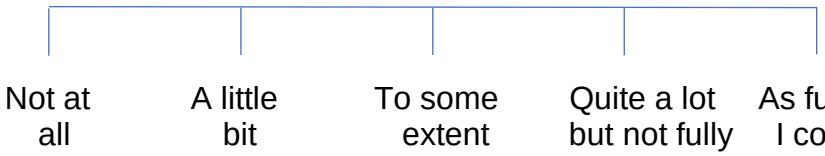
Goal #9 (if applicable): _ *The goal will be filled in in advance by the researcher*__



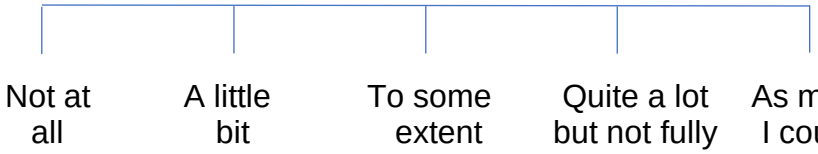
Goal #10 (if applicable): _ *The goal will be filled in in advance by the researcher*__



Goal #11 (if applicable): _ *The goal will be filled in in advance by the researcher*__



Goal #12 (if applicable): _ *The goal will be filled in in advance by the researcher*___



Your personal goals

The personal goals that we're interested in today are your most important goals today, and whether they have changed since the last time we met.

To refresh your memory on what we mean when we talk about personal goals, we are interested in understanding you and your experiences as you deal with a recent diagnosis of breast cancer, based on the things that you plan to do that are important to you. We call these your "**personal goals**". We all have personal goals, from the ordinary to the extraordinary. Our goals define how we spend our time and energy.

The personal goals that we're interested in today are the goals that **you're currently doing or considering doing**.

Goals may be related to **any aspect of your daily life**, from the very common things that most people do, to the very specific things that perhaps only you do! They can be related to your health, work, home, and community, among others. Please think of goals in this broad way and in relation to what you are doing at this time.

Some examples of personal goals

Personal goals may be focussed on:

- Something you want to achieve — "*Increase my exercise to 3 times a week"*
- Something new — "*Approach life with the happiness I feel today"*
- Something you have been doing for years — "*Walk my dog every morning*"
- Something you want to avoid — "*Stay away from sugar*"
- Something you want to do — *"Enjoying a night out with friends"*
- Something you feel you ought to do — "*Call my brother more often*"

We are also interested in finding out what you think and how you feel about these personal goals and activities, how challenging or stressful they are, and so on.

Please turn the page to start.

What are your most important personal goals?

How do you think and feel about your goals?

What are your 6 most important personal goals today?

On the table on the next page, in the column on the left, is your list of important personal goals that you identified the last time we met. **Please review the list and think about whether it still reflects your most important goals, or whether any have changed.**

1. If you wish to **remove a goal**, draw a line through it (for example, my goal).

2. Underneath each goal you will find space to **add a new important personal goal** or **modify your goal**.

3. It's OK to have fewer than 6 goals if that's how many you have. If you feel that you have no important personal goals now, skip the next few pages and turn to **page 10.**

How do you think and feel about your goals?

On the following page, we would like you to consider how you think and feel about your goals.

1. On page 9 is a list of these dimensions and a more detailed explanation of what each one means. Please **detach the list for easy reference** and refer to it as needed while you rate your goals.

2. Please turn to the next page (page 8) and **follow the instructions** at the top of the page.

INSTRUCTIONS

STEP 1: Update your list of important goals. Scratch out any goals that are no longer important and add any new goals that you plan to do in the column on the left.

STEP 2: Please rate from 0 to 10 how you think and feel about each goal in the dimensions along the top. Please use the definitions on page 10. *Do not complete ratings for goals from your previous list that you have scratched out.* If you feel a dimension is **not relevant** to one of your goals, you may put an "X" in the space instead of a number, but please **try to rate each goal on all dimensions if possible.**

		What do you think about what you are doing?								How do you feel about what you are doing?				
	Goals	Challenge	Likelihood of Success	Autonomy	Intention	Attention	Support	Time adequacy	Self-identity	Hopeful	Scared	Sad	Happy	Stressed
1	Goal will be filled in by researcher in advance Or new goal: _____													
2	Goal will be filled in by researcher in advance Or new: _____													
3	Goal will be filled in by researcher in advance Or new: _____													
4	Goal will be filled in by researcher in advance Or new: _____													
5	Goal will be filled in by researcher in advance Or new: _____													
6	Goal will be filled in by researcher in advance Or new: _____													

Goal Dimension Definitions

1. Challenge

How challenging do you think this goal will be?
(Use **10** if you think it will be extremely challenging, perhaps more than you can handle, and **0** if you think it will be not at all challenging – almost boring.)

2. Likelihood of Success

How successful do you believe this goal will be?
(Use **10** if you expect the goal to be entirely successful, and **0** if you think the goal will turn out to be a total failure.)

3. Autonomy

How much is this goal one which you feel you will pursue autonomously, that is, you will be engaged of your own free will in the goal, not because anyone else wants you to do it.
(Use **10** if you will be engaged in this goal entirely of your own free will, and **0** if this goal is one that you feel totally obliged to complete because of or for someone else.)

4. Intention

How much do you intend to pursue this goal, that is, how much do you want to pursue this goal?
(Use **10** if you fully intend to pursue the goal, and **0** if you do not intend to pursue it at all.)

5. Attention

How much attention do you think you can give to this goal?
(Use **10** for a goal that you plan to give your full attention, and **0** for one that you plan to give no attention at all.)

6. Support

To what extent do you feel this goal will be supported by other people? Support may come in different forms, e.g. emotional (encouragement, approval), financial (money, material possessions) or practical (active assistance).
(Use **10** if you feel other people will give full support for the goal, and **0** if there will be no support at all.)

7. Time Adequacy

Do you have enough time to spend working on this goal?
(Use **10** if you feel the amount of time you have will be perfectly adequate, and **0** if you feel that the amount of time you will have to spend working on the goal will not be at all adequate.)

8. Self-Identity

All of us have things we do that we feel are typical or truly expressive of us. These things can be thought of as our "trade marks". For example, some people engage in sports every chance they get, others prefer to read, others prefer to socialize. **Think of what your own personal "trade marks" are, and then rate this goal on the extent to which it is typical of you.**
(Use **10** if a goal is very typical of you, and **0** if it is not typical at all.)

9 – 13. Feelings (hopeful, scared, happy, sad, stressed)

To what extent do you feel each emotion while thinking about doing each goal?
(Use **10** if you experience the emotion very strongly, and **0** if you don't feel it at all.)

A little more about your treatment

We hope to learn more about women who are interested in integrative oncology. All of the information you share with us will be combined with everyone else in the study, so that it will not be used to identify you specifically.

1. **Are you currently receiving treatment for breast cancer, besides any hormone therapy? (E.g. radiation, chemotherapy, surgery, etc.)**

   ☐ Yes

   ☐ No

   ☐ I prefer not to answer

2. **Are you currently receiving any complementary therapies (at the Ottawa Integrative Cancer Centre, or at other centres)?**

   ☐ Yes

   ☐ No

   ☐ I prefer not to answer

Thank you!

This is the end of the final questionnaire that you will complete for this study. Thank you very much for sharing this information about your personal goals and how you think and feel about them for this study. It is truly appreciated.

As always, please don't hesitate to ask if you have questions at any time.

Thank you again,

Andrea

T3 Interview Guide

Recording

- *Audio record* - make sure I don't miss anything you say. *Ask permission.*
- May also *jot* notes *by hand*

YES - You are **in charge**. / You can **turn it off** at any time. *Show how* / Tell – turning it on

NO - OK! I will just take notes **by hand**.

No obligations & transcripts

- You don't have to answer any questions that **you do not want to answer**
- You can **stop** the discussion at any time.

- Later, I will **listen** to the tape & **write** down our conversation **word for word** – *transcript*
- Any information you share that can **identify yourself or someone else** during this discussion will be **removed** in the transcript.

Time

- The discussion should take about **45 minutes**
- Is there a certain time that you **need to leave** by?
- I have a **series of questions.** Want to be **respectful of your time**, so I'm going to try to **keep the conversation about your goals flowing**.
- Are you **ready to begin**?

Introduction

- Today: the **pursuit** of **2** your **personal goals** over the past <3 / 4> months, and the things that **helped** you pursue your goals, and the things that **made it challenging**.
- Your **thoughts** and **feelings**
- **No wrong or right** answers;
- All feelings and thoughts are **natural** and **normal**.

- **Factors:** think of as things or feelings or thoughts.

Examples

✓ **Physical**: maybe you had **less energy** than you expected
✓ **Emotional**: the goal made you **happy**, so you wanted to work on it more
✓ **External**: a **friend helped** you / many **chemo appointments** → no time for goal
✓ **Internal**: you felt **motivated** to work on it / you felt **too stressed** to think about it

- ✓ **One of other goals**: e.g. **exercise every A.M.** and **listen to music every A.M.**
  - **Negative**: You didn't have time for both; chose one
  - **Positive**: Did both at same time

Confirm the goal to discuss

GOAL 1: Looking at the 6 goals you have, which goal do you feel you have *pursued the least?*

GOAL 2: I'd like to turn to the goal that you feel you have pursued *the most.*

*** If multiple:* CHOOSE THE ONE MOST IMPORTANT TO YOU **

Pursuit assessment

Thinking about the last 3/4 months, have you been able to pursue this goal as much as you'd hoped?

Barriers

OK, **I'd like to chat** about things that made it hard for you to pursue [goal].

In your opinion, what made it difficult for you to work on this goal?

- PROMPT: How did *barrier* make it difficult?
- PROMPT: If *time*, what things did your time get spent on?
- PROMPT: Is there a deeper cause?
- PROMPT: Was there an interrelated factor?
- **LAST PROMPT: Was there anything else besides what we have already talked about that made it difficult?**

Facilitators

OK, **I'd like to chat** about things that helped you pursue [goal].

In your opinion, what helped you to work on this goal?

- PROMPT: How did *facilitator* help?
- PROMPT: Is there a deeper cause?
- PROMPT: Was there an interrelated factor?
- **LAST PROMPT: Was there anything else besides what we have already talked about that helped?**

Cancer treatment - ***if participant said 'yes' to cancer treatment question at T2 or T3***

You mentioned on the questionnaire that you were/are receiving cancer treatment. Did the treatment make it difficult for you to pursue this goal?

- PROMPT: How?

Breast cancer side effects

Did you experience any side effects from breast cancer, *<beyond the side effects from treatment that we've already discussed,>* that hindered your pursuit of goals?

- PROMPT: How?

Other goals

Did any of your other goals (on the list or not) affect your pursuit of this goal, either by helping or making it difficult?

- PROMPT: How?

Head Start

Did participating in Head Start affect your pursuit of this goal, by helping or making it difficult?

- PROMPT: How?

Complementary therapy *If participant said 'yes' to receiving CT at T2 or T3*

You mentioned you were/are receiving complementary therapy. Did receiving these therapies affect your pursuit of this goal?

- PROMPT: How?

Wrap-up

1. **How do you feel generally about how much you've been able to pursue your goals?**

2. Those are all of my questions. Is there **anything else that you wish** I had asked you?
3. **Thank you** very much for taking the time to talk to me today.

4. **Study results:** Are you interested in receiving? Email or post?

Appendix 7 – Barriers and Enablers of Goal Pursuit: Definitions and Select Quotations from Participant Interviews

BARRIERS

1. The experience of breast cancer treatment

Definition: The experience of living with breast cancer and/or undergoing breast cancer treatment reduced a participant's resources (physical, tangible, emotional) available for goal pursuit.

a. The physical effects of breast cancer treatment

Participants described feelings of illness and lack of energy following treatment that prevented them from pursuing their goals:

"Like one is your energy, it [cancer] zaps you. You pretty much have a wasted week after your chemo, trying to just recover from your sessions…I had an unexpected second surgery that I think really sapped me of my spirit and my energy." (Participant #2)

Severe side effects from treatment made it impossible for one participant to pursue her goals at all:

"Some days, my goal was just to make it…from the bed to the ensuite [bathroom]. Without passing out. Like it was – those were goals...It was more daily survival, instead of goals. Than thinking about happiness and meditating and whatever else, exercising. Yeah, no. That's not happening…Anything long-term – long-term is surviving this." (Participant #6)

b. Medical appointments

Participants described how having a high number of medical appointments reduced the time available for goal pursuit and disrupted daily routines.

"The thing that's gotten most in my way is appointments...I feel really grateful for the medical system that we have in Canada…At the same time, it's not anyone's fault but it's the time factor to make sure that I make all these appointments and that I get to them. It can be really, really stressful." (Participant #2)

"I think it was just a matter of feeling really out of routine, out of my life in a way that it was really hard for me to get focused in on any aspect, you know…all of the appointments, the surgeries, obviously..." (Participant #7)

"I wanted to go to the office once a week at least for half a day. I haven't been able to do that, mostly because of all of the appointments I've had." (Participant #2)

c. The emotional or psychological effects of breast cancer treatment

Several women also spoke about emotional or mental fatigue that followed adverse outcomes or experiences with treatment and hindered their ability to pursue their goals:

"I said to someone the other day, 'I have a lump on my breast,' [touches breast] like I was like expecting my breast to be there and it wasn't…right, it's gone. It's got this whole mental fatigue component to it. All that emotional stuff is taxing on your energy. So when it comes time to pursue goals that are not cancer-related, it's hard to have the energy and the motivation, you know, to do it. It has to be a high motivator, you know, to be able to get the energy to do it." (Participant #2)

"…this has been extremely emotional. Because when you can't figure out if you can make it to the bathroom or not and stand up alive or stay upright without crawling, which I ended up doing a lot…emotions play heavily on you…yeah, it was very depressing, very depressing." (Participant #6)

"I think just a lot of head chatter going on…What was coming next, it's been a long journey for me. I still don't have all the answers, so there's still a lot of unknowns for me…I'm into the eighth month of lots of uncertainty…I spent a lot of time on [running through possible scenarios], which I don't know what I could have done differently really, I tried to minimize it as much as I could, but it's difficult when you're in this kind of situation and you don't know what's coming." (Participant #7)

2. Fear

Definition: A feeling of being scared of the consequences or outcomes of goal pursuit, or a feeling of being scared that prevented the participant from pursuing a goal

"I was quite scared about the whole thing because I was really getting out of breath, and just the whole thought of exercising and moving – there was a real lethargy there. I just didn't feel strong enough." (Participant #2)

"It's really been trying to clear those fears behind setting boundaries – one of them is, if I set my boundaries, I'll be alone… so I did a lot of things to be with people, but I gave up myself." (Participant #3)

"For that particular goal, it's also dealing with mortality and death too...so although there is a sense of urgency, it's dealing with something that you don't want to deal with as well…once you're in diagnosis, it's even more important but it's even further away from you wanting to touch it because it's dealing with something that's more possible." (Participant #4)

3. Being more challenging than expected

Definition: Thoughts or feelings that the process of goal pursuit or what would have been required of participants to pursue goals would be more difficult than expected

"[My child's] dad is very, very toxic and difficult to deal with, and it involves him, obviously, because one of the factors in putting a will together means I need to factor in what is going to happen to my [child] if something happens to me, which will then involve…him… it's…just stressful even thinking about engaging with that person." (Participant #4)

"It just seemed more challenging than I expected it to be, to be able to focus and to do that for myself. It's not a matter of time, I had time…or opportunity – that wasn't it. It was definitely within me…it just took tremendous energy to shut down all of the chatter in my head and it was easier just to not, you know." (Participant #7)

A few participants spoke about the place or aspects of the setting where the goal was being or would have been pursued as barriers. One such barrier was the weather:

"The only reason that's the hardest one is I didn't realize…the weather thing. So my first chemo treatment, that whole week, not only did it rain but it poured every single day, and it was cold and it was humid…Especially at the beginning, like I had surgery, and then I had my port put in and you're not supposed to get wet. And the rain was just so bad." (Participant #1)

Another was the workplace environment, where the goal pursuit would have taken place:

"I think in some ways I was feeling very, very taxed, my mental capacity and the time factor…working late, those kinds of things. Those are the things that I don't want to go back to…I think that the stress level had something to do with cancer…I'm afraid to get back into it and have a, I don't know if it would cause a re-occurrence." (Participant #2)

In reflecting on the effect of attending a support group on her goal, one participant said:

"If I go to a group and I find it's not good for me, then I need to honour that instead of getting angry…and say it doesn't work for me, at least not this group. I didn't feel like I'd really honoured myself." (Participant #3)

4. Lack of alignment with self-identity or values

Definition: Thoughts or feelings that the goal did not fit with one's identity or values

A few women talked about the difficulty in shifting from their normal practices of taking care of others to focus on oneself and one's own goals:

"Having this diagnosis hasn't made me make other people less important and make me more important. It hasn't changed that part of who I am. Which means it hasn't made me still prioritize myself...I think that I assumed…that you do a one-eighty. So, oh you have a diagnosis of whatever, something life threatening or critical. And you're going to go from, in your typical life, you're taking care of everyone else…to oh wow, I'm now going to not worry about other people and I'm going to focus on myself. I mean, is that realistic? I think that's what people hope to do, and think they're going to do…I don't know how successful people are at doing that. It seems that for me, I thought that I would have been able to do that, but it makes sense that I didn't. Just completely stop taking care of everyone else and then be able to prioritize myself when I never do." (Participant #4)

"It's hard to be selfish which is what you need to be in treatment with cancer, you need to be selfish. I was told yesterday…most women that end up getting cancer like this were 'yes women' before…[women] who just did everything for everybody. And that this is a real reality check and everything happens for a reason, so maybe it is just a reality check to kind of be selfish for a while and realize that we're important too, you know." (Participant #6)

One woman talked about her goal as being something she had not liked doing before her breast cancer diagnosis:

"I don't like to feel like I'm imposing on others or demanding. I don't want to be that kind of person. So I'd rather not bother someone. And I guess just the sense that I can do it myself, I don't need help." (Participant #7)

5. Goal interference/competing priorities

Definition: Pursuing other activities, goals or responsibilities outside of treatment requirements reduced the participant's resources (emotional, time, etc) available to pursue the goal

For some, the priority was taking care of oneself mentally and physically:

"I wanted to go to the office once a week at least for half a day…there's some days when there isn't an appointment, like tomorrow – well I have fitness tomorrow… when there's nothing on the calendar, you think, that's a day of rest." (Participant #2)

"Me focusing on my treatment meant…not having to take care of other people…moving towards taking care of myself and prioritizing myself probably made that goal [making a will] less important. Because making a will is not taking care of yourself at all. It's really taking care of everyone else." (Participant #4)

One participant needed to be accompanied by another adult to pursue her goal, but found that her partner was not available to provide that support because somebody needed to stay home with their children:

"Unfortunately, when my kids are home, my husband can't walk with me, and up until today, one of our kids was always at home." (Participant #1)

a. Caring for parents or children (sub-theme)

"My mother she's also she's not well, so I have to help care for her…so that gets in the way too. And all her appointments." (Participant #2)

"When I'm getting better she starts asking me to make food for her, which is what, as a mom, you do. So when I'm not in that state [of extreme physical illness], it's hard for me not to be up and taking care of her even though I've been really, really sick. It's hard to be selfish which is what you need to be in treatment with cancer, you need to be selfish." (Participant#7)

ENABLERS

1. Social supports

Definition: assistance provided by people within a participant's social networks; types of assistance include but are not limited to: physical, emotional, financial, tangible, informational

Support came from a wide range of people: partners, other family members, friends, work colleagues, medical care providers, and communities. One woman talked about how having several family members living with her supported her goal pursuit:

"My family were fantastic, they were just right there and what do you need me to do, what can I do for you. So it certainly made that easier for me to ask for help...Initially I felt that it was asking for help that was going to be difficult because I don't like to ask for help, but then it was more about accepting it because they were quite willing to jump in and [help]." (Participant #7)

Another spoke about actively choosing members of her social network that would provide emotional support for her goal pursuit:

"I've made a lot of changes. And so the people that I've chosen to have around me are those people that understand. So it makes it easier for me to [pursue my goal]…and the response [to my goal pursuit] is just great. It's positive." (Participant #3)

Social supporters provided emotional and tangible support for goal pursuit. A few women mentioned that their social supports reduced their social or familial responsibilities, which helped them focus on goal pursuit:

"Because of the support that I get at home [from my husband], I'm able to take time to breathe, take time to eat, and take time to plan...sometimes it's just simply taking my kids to the park…so I have time to either do some breathing exercises or some meditating." (Participant #1)

"Whenever I'm engaging with people, whether it's at work or family or friends, my first priority becomes helping them with their problems…So part of the way everyone in my life helped me make that shift was for them to give me permission to not worry or not take care of them. I still haven't prioritized myself, but I have disengaged with having to take care of other people as much." (Participant #4)

2. Prioritization of the goal

Definition: Conscious decision to pursue a goal, perhaps instead of pursuing other activities (i.e. by creating strategies, overcoming barriers, etc)

"I'm choosing that [goal] as a priority." (Participant #2)

"Because it's been a goal, even if I wasn't feeling good, I didn't feel like I had the energy, I would still force myself to go out and go for a walk." (Participant #1)

One woman, however, came to feel the opposite about her highly pursued goal, that it was simply not a priority and that this mitigation of the goal's importance made it easier for her to attain:

"It's just there are other things that are just so much more important. Whereas that was important in the beginning, because I was feeling fine...it became less important what I looked like and more important for me to survive…in the beginning, I almost didn't have chemo because I didn't want to lose my hair. It was the most important thing. But after experiencing what I've experienced…it's just

not an issue. It's so irrelevant...I don't know if I've successfully pursued it, it just became a non-issue." (Participant #6)

3. The experience of living with breast cancer and through treatment

Definition: Aspects of the experience of living with breast cancer and/or undergoing breast cancer treatment provided motivation for goal pursuit.

For a few women, motivation for a successful recovery or better health in the future enabled their goal pursuit:

"I never saw the cancer thing as taking away my goals, I saw it more as a reason to make sure they happen more." (Participant #1)

"That's part of the gift that's come with this cancer journey…seeing where I wasn't honouring myself... But there's a bigger message that cancer has taught me that if I do not take care of myself, I will die. This is saying, you nurture everybody else. But if you don't nurture yourself, you're not going to make it...cancer has given me the strength to do it." (Participant #3)

"I really identified that [goal] as to be very, very helpful in my recovery." (participant #2)

One woman mentioned that feeling better after treatment helped her to eventually begin pursuing her less pursued goal, and one woman identified psychological consequences that enabled her goal pursuit:

"Life gives you opportunity for learning and growth and even [with] something like cancer you can find that that happens and certainly I've tried to look for that, and that ties into the positive attitude goal too: what can I learn from this, how can I turn this into something of benefit for me." (Participant #7)

4. Changing definition of progress during goal pursuit

Definition: Making the meaning of what it means to advance towards goal achievement or attainment, different over time - consciously or unconsciously

"My thing was to stay positive but I guess the positive part is just more taking the time to have things in place so that when things are stressful, I don't have to worry because everything is already in place, including having time to go for a walk, or be able to meditate, or breathing exercises." (Participant #1)

"My goal was…me trying to be everything to everybody…to find balance between relationship and friendship and motherhood and work and going through treatment all the same time...the word balance means imbalance, I guess. Where before my work life balance was probably imbalanced more to work and less to personal. Where now it's reversed…for my purpose, it is balance. It's picking one [life] over the other [work] for this process… I think the word 'life' in that equation would be treatment…I think at the time I might have been thinking personal. But now I think it's more specific to cancer patient role…So the goal's been really, it wasn't about balance actually. It's probably more about focusing on one thing...I still haven't really fully focused on myself, but I've disengaged with taking care of other people… And the long-term one…will be to balance, truly what I originally imagined." (Participant #4)

"I don't think I would say I successfully pursued it, it just happened. I had to ...I was very, very sick...The second [chemotherapy session] I guess, that's when the symptoms started...My world now revolves around cancer. There's nothing else in it." (Participant #6)

5. Identifying and utilizing helpful resources

Definition: The process of finding, recognizing and perhaps using things, people, strategies, and other assets to assist with goal pursuit

"I have invested in a hat and I have a sweater so that I'm not exposing myself to too much sun; I had to prep myself to go for walks." (Participant #1)

"Getting into a routine now, I think routine is really important. I do it mostly on the same days, at the same time." (Participant #2)

6. Having time

Definition: Finding, or being given, time to pursue a goal that would normally be occupied with other daily or usual responsibilities

"Having more time to sit and contemplate helped me to really evaluate my life, and how I was living it and how I'd like to be living it." (Participant #3)

"I have a little bit more me time by not being at work...I'm actually working on goals that I usually can't do because I'm working." (Participant #1)

7. Goal facilitation

Definition: Pursuing other goals within a woman's goal system or hierarchy

"I knew why I needed those goals [e.g. meditation] and it's just a matter of keeping them in everyday life to make everyday life less of a stress in general... I'm trying to make the habits that I have attainable so that I can be at work and doing them." (Participant #1)

8. Changing one's thinking

Definition: Making one's thoughts about the goal different

"One of the words that I left out was control, and the sense that I lost control of my life. That it was in other people's hands and there was very little that I could do about it, except that then I started to realize that, no, there were things that I could do, and continue to focus on." (Participant #7)

9. Head Start

Definition: Participation in the OICC's Head Start program

All but one woman (n=5) were asked directly if any aspect of participating in the OICC's Head Start program had enabled her goal pursuit. Most of the women felt that it had, by emphasizing

helpful or positive practices, teaching new skills or techniques for those practices, or by providing a sense of camaraderie through the small group format:

"I learned a whole bunch of new meditative things…I really don't do well with waiting…my last chemo treatment was seven hours. That's a really long time…And then you have people around talking about their illness or where they are. And not everybody is positive and not everybody is stress-free…I get that. But I definitely find that that's helpful for that because it helps me block out all of this external noise, and it makes the time go by more easily." (Participant #1)

"I think being willing to be open in the group, to talking about how I was feeling and what my issues were. And as we walked through all of it and to be willing to listen to suggestions, advice, any of that that came from the group, not just the leaders but any of the women in the group…I think some of the things that I've come out of it learning is the acceptance that I don't have control over anything. I can do what I can do but outside of that…Tying in with asking for help was also finding my voice for even dealing with the medical profession." (Participant #7)

A few women were unsure if the program enabled their goal pursuit, or felt that it did not:

"I think one of the things when I was doing the Head Start program was…we did an exercise…it was the most important things that you can do for yourself recovering from cancer and how to prevent a reoccurrence. And the first thing on that list was [her highly pursued goal]… there was some great pieces, a bit of yoga and some mindfulness. I wish there was more of that. It kind of aligned with my goal, but I don't know if it helped. I just know I should be doing it [her goal]. I can't say if the program supported me." (Participant #2)

10. Complementary therapy

Definition: Care, treatment, or services that support conventional cancer treatment and overall well-being, but do not treat the cancer itself[54]

"I've had massage therapy done as well, and acupuncture and it gives my body such a release from – I can't even explain it – from the flow of my body, that I'm less stressed in my body, and it just makes me a much happier person. I'm happier and more positive. It definitely helps relieve that kind of build up. Because I don't feel like my body's failing me, I feel like it's been re-energized, and that really helps too. And I also see an N.D. [naturopathic doctor]…It helps to know that my body's getting what it needs to protect itself during treatments and stuff, making it way less stressful." (Participant #1)

"Some of the therapies are looking at patterns from your childhood, and for me…it's going back and healing those patterns to enable me to be strong enough to set boundaries and know that I'll be OK, that I'll be loved and accepted…I can step more fully into my power and embrace my life and know I'm worthy of as much as everybody else. And so in that sense it's helped me." (Participant #3)

Chapter 6: Thesis Discussion

6.1 SUMMARY OF FINDINGS

The aim of this thesis was to examine several aspects of the personal goals of women with breast cancer. Towards this aim, I conducted two interrelated studies. In the scoping review (Manuscripts #1 and #2), I found very few studies (n=12) had been conducted on the personal goals of women with breast cancer where their goals had been set or elicited in the study. Among the included studies, there was significant variability across the included studies in terms of study design, objectives, methods, outcomes and reporting. The inclusion criteria, measurement and reporting of participant characteristics varied across the included studies. Eight studies evaluated an intervention which included personal goal-setting as a main component. Within these eight studies, no study used validated tools to elicit or set personal goals. Thus, I was unable to describe the results of studies that used validated tools, our fourth study objective.

In the second part of this thesis, I conducted a mixed-methods cohort study (Manuscripts #3 and #4) to explore goals of women recently diagnosed with breast cancer, specifically in an integrative oncology setting. Participants were moderately successful in pursuing their goals. I identified ten types of enablers and five types of barriers to goal pursuit. I found that all eight participants had at least one health goal, seven participants had at least one psychological goal, and seven had at least one social goal. Women generally had positive assessments of their goals, with ratings averaging 7.25 or higher (out of 10) for likelihood of success, autonomy, intention, support, self-identity, attention, time adequacy, and feeling hopeful and happy across all timepoints.

6.2 OUR FINDINGS

6.2.1 Personal goal-setting among women recently diagnosed with breast cancer

The scoping review was the first known review of personal goal-setting among women with breast cancer. Few of the studies that were identified in our review were also identified in a systematic review of life goals among people with cancer published by Hullmann and colleagues in 2015, with only one study included in both reviews.[1] Eligibility criteria related to populations and personal goals differed between the reviews and six of the studies included in our review had been published after Hullmann et al completed their review. Our study, therefore, was able to identify a small number of existing studies on personal goal-setting among women with breast cancer and to analyze elements of these studies. For example, we found that only half the included studies reported the time since breast cancer diagnosis.[2-7] Among these six studies, five reported a mean or mode time which ranged from 9 to 33 months, indicating that most of the included studies focussed on participants who had likely completed active treatment and were at a stage often considered as post-active treatment survivorship.[2-4,6,7] This is an important time to work with women living with experiences of breast cancer, but our findings show that women's personal goals shortly after a diagnosis of breast cancer have not been well-captured in the literature. We found only two studies whose populations were all or mostly women within one year of diagnosis.[5,6] In our cohort study, however, we focussed on women who have been recently diagnosed with breast cancer. The median time since diagnosis was 75 days. The first three months following a diagnosis can be characterized by uncertainty and the constraints and side effects that can accompany breast cancer treatment. Cancer, treatment and physical symptoms can hinder someone's individual resources necessary to pursue meaningful goals.[1,8]

This thesis explored personal goals among women with breast cancer at a time where lives may have been greatly disturbed and psychological well-being may have been negatively affected.[9-15]

6.2.2 The use of validated or published instruments to elicit or set personal goals

No study included in the scoping review used validated instruments to set or elicit personal goals. Several validated or published instruments exist which allow for the elicitation of idiosyncratic personal goals while also providing opportunities to compare goals by assessing them across factors that can vary across goals, such as goal importance or commitment to the goal.[16-19] In the scoping review, two studies used the Personal Strivings List to elicit goals, and in our cohort study, we used the Personal Projects Analysis to elicit goals and measure how participants thought and felt about their goals on several dimensions.[17-19] How people think and feel about their goals may be predictive of successful goal pursuit, and further, of their well-being.[18,20-22] Among people with cancer, higher goal importance is associated with better psychological outcomes.[23] Our cohort study suggests that women have positive thoughts and feelings about their important goals. Stakeholders providing supportive care to women recently diagnosed with breast cancer may choose to focus on goals perceived to be important. We were unable to conduct a planned analysis of goal dimensions and goal pursuit, but we recommend that future, larger studies do so.

6.2.3 Barriers and enablers of goal pursuit

Many studies have examined goal adjustment among women with breast cancer, the process of changing goals or changing the ways a person engages with her goals,[1,24-28] but no article, to the best of my knowledge, has identified their barriers or enablers of goal pursuit. In my cohort study, participants were able to make modest progress on the goals that they

considered important but were not able to pursue many of their goals as successfully as they had hoped, though all but one participant had at least one goal that they pursued a lot or as fully as they could throughout the study. This suggests that it is possible for women to identify at least one important goal that they can pursue with a relatively high degree of success. Supportive interventions may find it beneficial to focus on helping women to pursue a smaller number of goals. Two studies identified in the scoping review evaluated an intervention that helped women with breast cancer to find strategies to pursue their goals, concentrating on one to two goals per week.[29,30]

In our cohort study, we found that several women enabled goals by thinking about them differently or adapting to their situations at the time of goal pursuit and that other goals in their systems helped some women pursue a goal, which are consistent with previous research.[8,31] Cancer and its treatment hindered goal pursuit for all participants in our study and has been identified as a reason for goal interference in previous studies.[1,32] In our cohort study, however, we also observed that the experience of cancer also enabled goal pursuit for some women. Understanding the factors that help or hinder goal pursuit is a crucial step towards developing interventions that can help women set goals that they can successfully pursue after a breast cancer diagnosis and adjust or disengage from goals that are not successfully pursued.

6.2.4 Interventions supporting women with breast cancer to set and pursue goals

Helping women to identify the resources and experiences available may help to enable goal pursuit. Some studies have identified strategies that people with cancer use to adjust their personal goals.[27,33] The methods that people with cancer use to adjust or think about their goals can have an impact on psychological well-being. In our scoping review, we identified eight studies that described and evaluated a supportive, psychosocial intervention for women with

breast cancer where personal goal-setting was a major intervention component.[2-5,29,30,34,35] Five of these studies described specific results related to the goals set in the intervention.[3,4,29,30,35] Beyond identifying the barriers and enablers of goal pursuits, it is also important to begin to understand what components are effective to successful goal pursuit. Interventions that use effective strategies to help women identify and adjust goals that can be pursued while undergoing treatment may facilitate more successful goal pursuit and mitigate the negative effects of cancer-related interference on well-being.[1,33,36,37]

6.3 THESIS IMPLICATIONS

For institutions and organizations interested in patient-centred oncological care, particularly integrative oncology, where patient-centred care is a key tenet, personal goals represent outcomes that are important to an individual. They therefore help providers of supportive care and treatment understand the things that women are thinking about and the ways in which women want to focus their resources, such as time and physical energy, when living with a breast cancer diagnosis. Women with breast cancer themselves may review the findings of this thesis and find useful information on the kinds of goals and the types of barriers and enablers that have influenced the goal pursuit of other women recently diagnosed with breast cancer. My cohort study shows that women recently diagnosed with breast cancer have a variety of goals across multiple life domains.

Being able to successfully pursue our goals is important to well-being. Among women with breast cancer, well-being is challenged by the side effects of cancer and treatment and limitations on individual resources, which are diverted to caring for one's health. With this thesis, our goal was to gain a better understanding of some of the barriers and enablers to goal

pursuit specific to women living with breast cancer and to contribute new knowledge that can be used in developing new interventions, or enhancing existing ones, to support women recently diagnosed with breast cancer to identify and successfully pursue their goals. This thesis provides new information on the personal goal pursuit of women recently diagnosed with breast cancer, in particular, the barriers and enablers of their goal pursuit and several characteristics of their personal goals. It also identifies and synthesizes the existing literature on the personal goal-setting of women experiencing breast cancer treatment and/or recovery and identifies gaps in the literature that can be addressed by future studies.

Building upon the findings of this thesis, I recommend three potential areas for future research towards a goal of developing new or enhancing existing interventions that could effectively support women with breast cancer to set important goals and enable their pursuit:

1. **Elucidation of the mechanisms between personal goal-setting, goal pursuit and well-being.** While details on the mechanisms of personal goal-setting, goal pursuit, and well-being in the general population exist,[19,22,38-44] the mechanisms of goal pursuit in breast cancer populations are less well understood.[1,8,24-28,36] A review of the existing literature on the relationships between goal characteristics, goal processes and outcomes important to women with breast cancer would produce information that would be helpful for identifying specific pathways that can be effectively targeted by interventions supporting goal-setting and pursuit.
2. **A deeper exploration of the characteristics of goals most successfully pursued.** In this thesis's cohort study, nearly all women were able to successfully pursue at least one goal over three to four months. Future studies could examine the ideal number of goals actively pursued in the first few months following a breast cancer diagnosis and the characteristics of

personal goals that women do successfully pursue (for example, goal dimensions, life domains of the goals). While my cohort study examined the personal goals of women recently diagnosed with breast cancer and taking part in an integrative oncology, educational, psychosocial support program, future studies could examine goal characteristics in a broader population of women with breast cancer. This could enable greater generalizability of findings.

3. **Development and evaluation of a personal goal intervention.** My scoping review identified eight studies with a goal-setting intervention.[2-5,29,30,34,35] Most of these studies, however, were pilot or feasibility studies primarily focused on intervention acceptability or feasibility rather than participant-centred outcomes.[2,4,29,30,35] My cohort study was a one-group study with a small sample size. This produced useful descriptive information but did not allow for comparison across populations. Larger studies are needed that include control groups and can produce generalizable information on personal goal-setting and/or pursuit and outcomes important to women with breast cancer.

Further studies are required to more thoroughly understand how women with breast cancer assess their personal goals and the factors that contribute to their successful pursuit of those goals. Studies in any of the above recommended areas would represent useful, appropriate next steps in building a robust evidence base ultimately aimed at providing support for women to set and pursue goals important to them during their breast cancer treatment and recovery journeys.

6.4 REFERENCES FOR CHAPTER 6

1. Stefanic N, Caputi P, Iverson DC. Investigating physical symptom burden and personal goal interference in early-stage breast cancer patients. Support Care Cancer. 2014;22:713–20.

2. Cheung EO, Cohn MA, Dunn LB, Melisko ME, Morgan S, Penedo FJ, et al. A randomized pilot trial of a positive affect skill intervention (lessons in linking affect and coping) for women with metastatic breast cancer: A Positive Affect Intervention for Women with Metastatic Breast Cancer. Psychooncology. 2016. doi:10.1002/pon.4312.

3. Graves KD, Carter CL, Anderson ES, Winett RA. Quality of life pilot intervention for breast cancer patients: use of social cognitive theory. Palliat Support Care. 2003;1:121–34.

4. Harcourt D, Griffiths C, Baker E, Hansen E, White P, Clarke A. The acceptability of PEGASUS: an intervention to facilitate shared decision-making with women contemplating breast reconstruction. Psychol Health Med. 2016;21:248–53.

5. Nápoles AM, Ortíz C, Santoyo-Olsson J, Stewart AL, Gregorich S, Lee HE, et al. Nuevo Amanecer: results of a randomized controlled trial of a community-based, peer-delivered stress management intervention to improve quality of life in Latinas with breast cancer. 2015;105 Suppl 3:e55.

6. Searls K, Fawcett J. Effect of Jin Shin Jyutsu energy medicine treatments on women diagnosed with breast cancer. J Holist Nurs Off J Am Holist Nurses Assoc. 2011;29:270–8.

7. Sullivan-Singh SJ, Stanton AL, Low CA. Living with limited time: Socioemotional selectivity theory in the context of health adversity. J Pers Soc Psychol. 2015;108:900–16.

8. Peterman A, Lecci L. Personal projects in health and illness. In: Little BR, Philips SD, Salmela-Aro K, editors. Personal project pursuit: goals, action, and human flourishing. Mahwah, N.J.: Lawrence Erlbaum Associations; 2007. p. 329–53.

9. Burgess C, Cornelius V, Love S, Graham J, Richards M, Ramirez A. Depression and anxiety in women with early breast cancer: five year observational cohort study. BMJ. 2005;330:702.

10. Davis LE, Fulton C, Bubis LD, Sussman J, Moody L, Barbera L, et al. Patient-reported symptoms following mastectomy alone or lumpectomy plus radiation for early stage breast cancer: a cohort study. Breast Cancer Res Treat. 2019;175:721–731.

11. Epping-Jordan JE, Compas BE, Osowiecki DM, Oppedisano G, Gerhardt C, Primo K, et al. Psychological adjustment in breast cancer: Processes of emotional distress. Health Psychol. 1999;18:315–26.

12. Henselmans I, Helgeson VS, Seltman H, de Vries J, Sanderman R, Ranchor AV. Identification and prediction of distress trajectories in the first year after a breast cancer diagnosis. Health Psychol. 2010;29:160–8.

13. Schmid-Büchi S, Halfens RJG, Müller M, Dassen T, van den Borne B. Factors associated with supportive care needs of patients under treatment for breast cancer. Eur J Oncol Nurs. 2013;17:22–9.

14. Weisman AD, Worden JW. The existential plight in cancer: significance of the first 100 days. Psychiatry Med. 1976;7:1–15.

15. Zabora J, Brintzenhofeszoc K, Curbow B, Hooker C, Piantadosi S. The prevalence of psychological distress by cancer site. Psychooncology. 2001;10:19–28.

16. Stevens A, Beurskens A, Köke A, van der Weijden T. The use of patient-specific measurement instruments in the process of goal-setting: a systematic review of available instruments and their feasibility. Clin Rehabil. 2013;27:1005–19.

17. Little BR. Personal projects: a rationale and method for investigation. Environ Behav. 1983;15:273–309.

18. Little B. Generative Contexts of Personal Projects Analysis. In: Little BR, Philips SD, Salmela-Aro K, editors. Personal project pursuit: goals, action, and human flourishing. Mahwah, N.J.: Lawrence Erlbaum Associations; 2007. p. 3–49.

19. Emmons RA. Personal strivings: An approach to personality and subjective well-being. J Pers Soc Psychol. 1986;51:1058–68.

20. Palys TS, Little BR. Perceived life satisfaction and the organization of personal project systems. J Pers Soc Psychol. 1983;44:1221–30.

21. Christiansen CH, Backman C, Little BR, Nguyen A. Occupations and Well-Being: A Study of Personal Projects. Am J Occup Ther. 1999;53:91–100.

22. Sheldon KM, Kasser T. Goals, Congruence, and Positive Well-Being: New Empirical Support for Humanistic Theories. Nal Humanist Psychol. 2001;41:30–50.

23. Hullmann SE, Robb SL, Rand KL. Life goals in patients with cancer: a systematic review of the literature: Life goals in patients with cancer. Psychooncology. 2016;25:387–99.

24. Mens MG, Scheier MF. The Benefits of Goal Adjustment Capacities for Well-Being Among Women With Breast Cancer: Potential Mechanisms of Action: Goal Adjustment, Well-Being, and Breast Cancer. J Pers. 2016;84:777–88.

25. Lam WWT, Yeo W, Suen J, Ho WM, Tsang J, Soong I, et al. Goal adjustment influence on psychological well-being following advanced breast cancer diagnosis: Goal adjustment and psychological well-being. Psychooncology. 2016;25:58–65.

26. Thompson E, Stanton AL, Bower JE. Situational and Dispositional Goal Adjustment in the Context of Metastatic Cancer. 2013;81:441–51.

27. Stefanic N, Caputi P, Lane L, Iverson DC. Exploring the nature of situational goal-based coping in early-stage breast cancer patients: A contextual approach. Eur J Oncol Nurs. 2015;19:604–11.

28. Wrosch C, Scheier MF, Miller GE, Schulz R, Carver CS. Adaptive self-regulation of unattainable goals: goal disengagement, goal reengagement, and subjective well-being. Pers Soc Psychol Bull. 2003;29:1494–508.

29. Lyons KD, Hull JG, Kaufman PA, Li Z, Seville JL, Ahles TA, et al. Development and Initial Evaluation of a Telephone-Delivered, Behavioral Activation, and Problem-Solving Treatment Program to Address Functional Goals of Breast Cancer Survivors. J Psychosoc Oncol. 2015;33:199–218.

30. Hegel MT, Lyons KD, Hull JG, Kaufman P, Urquhart L, Li Z, et al. Feasibility study of a randomized controlled trial of a telephone-delivered problem-solving-occupational therapy intervention to reduce participation restrictions in rural breast cancer survivors undergoing chemotherapy. Psychooncology. 2011;20:1092–101.

31. Riediger M. Interference and facilitation among personal goals: age and associations with well-being and behavior. In: Little BR, Philips SD, Salmela-Aro K, editors. Personal project pursuit: goals, action, and human flourishing. Mahwah, N.J.: Lawrence Erlbaum Associations; 2007. p. 119–43.

32. Paul A. What Are the Personal Goals of Women with Breast Cancer and What Hinders Goal Achievement? (S736). J Pain Symptom Manage. 2017;53:429.

33. Janse M, Sprangers MAG, Ranchor AV, Fleer J. Long-term effects of goal disturbance and adjustment on well-being in cancer patients. Qual Life Res. 2016;25:1017–27.

34. Wiljer D, Urowitz S, Frasca E, Nyhof-Young J, Secord S, Walton T, et al. The Role of a Clinician-Led Reflective Interview on Improving Self-Efficacy in Breast Cancer Survivors: A Pilot Study. J Cancer Educ. 2010;25:457–63.

35. Wiljer D, Urowitz S, Jones J, Kornblum A, Secord S, Catton P. Exploring the use of the survivorship consult in providing survivorship care. Support Care Cancer. 2013;21:2117–24.

36. Stefanic N, Iverson DC, Caputi P, Lane L. Examining the influence of personal goal interference and attainability on psychological distress in non-metastatic breast cancer patients. Eur J Cancer Care (Engl). 2016. doi:10.1111/ecc.12494.

37. Schroevers M, Kraaij V, Garnefski N. How do cancer patients manage unattainable personal goals and regulate their emotions? Br J Health Psychol. 2008;13:551–62.

38. Locke EA, Latham GP. Building a practically useful theory of goal setting and task motivation: A 35-year odyssey. Am Psychol. 2002;57:705–17.

39. Ryan RM, Deci EL. Self-determination theory and the facilitation of intrinsic motivation, social development, and well-being. Am Psychol. 2000;55:68–78.

40. Carver CS, Scheier MF. Principles of self-regulation: Action and emotion. In: Higgins ET, Sorrentino RM, editors. Handbook of motivation and cognition: Foundations of social behavior. New York, NY: The Guilford Press; 1990. p. 3–52.

41. Freund AM. Differentiating and integrating levels of goal representation: a life span perspective. In: Little BR, Philips SD, Salmela-Aro K, editors. Personal project pursuit: goals, action, and human flourishing. Mahwah, N.J.: Lawrence Erlbaum Associations; 2007. p. 247–70.

42. Klug HJP, Maier GW. Linking goal progress and subjective well-being: a meta-analysis. J Happiness Stud. 2015;16:37–65.

43. Sheldon KM, Kasser T. Pursuing Personal Goals: Skills Enable Progress, but Not all Progress is Beneficial. Pers Soc Psychol Bull. 1998;24:1319–31.

44. Brunstein JC. Personal Goals and Subjective Well-Being: A Longitudinal Study. J Pers Soc Psychol. 1993;65(5):1061-1070.