

## **The Rationales for and Challenges with Employing Arts-based Health Services Research (ABHSR): A Qualitative Systematic Review of Primary Studies**

Additional File 1

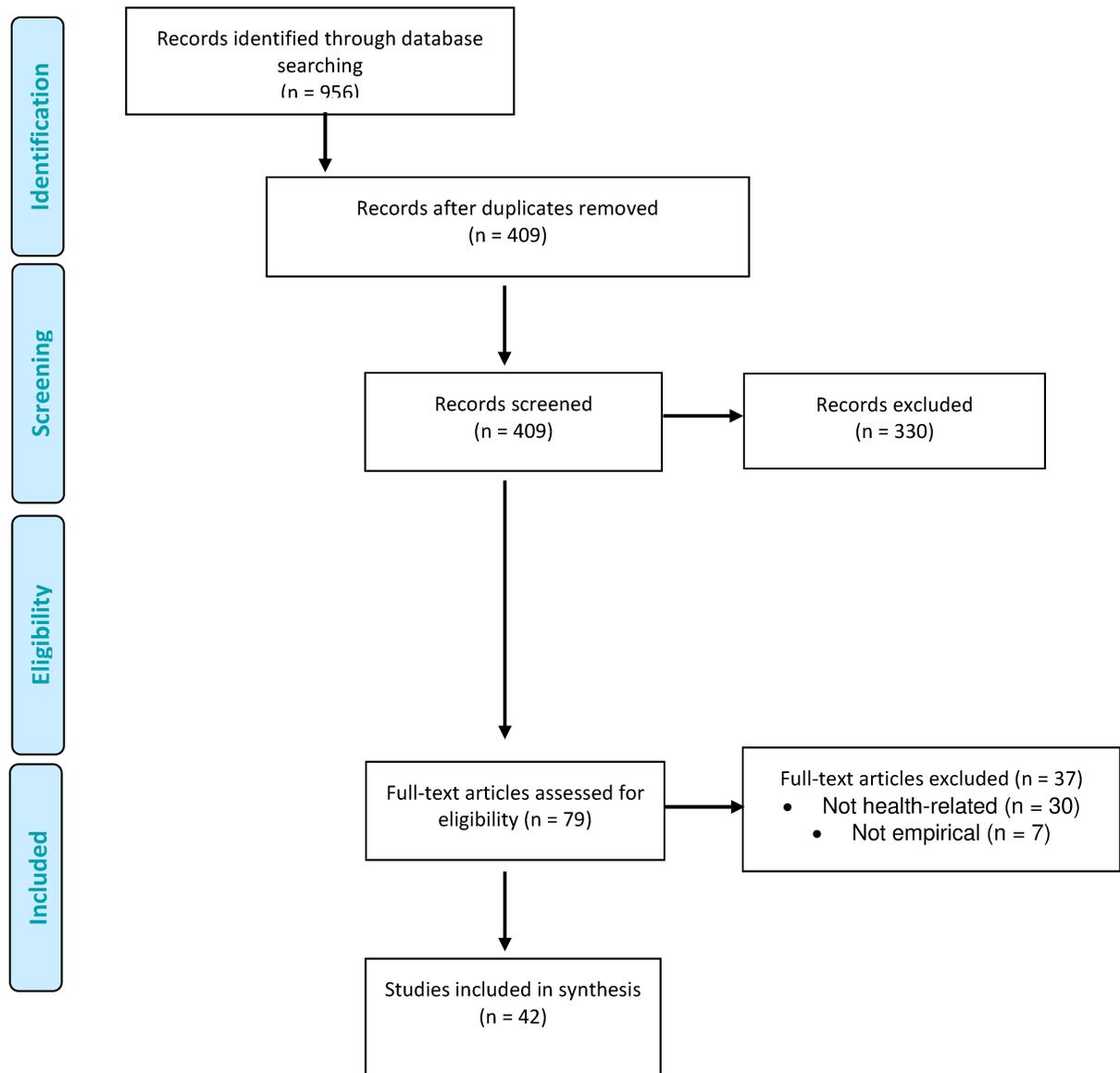
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## Part A: Search Strategy Example

**MEDLINE:** 1946 to November 30, 2018

- 1/ photovoice\*.mp [531]
- 2/ photo-voice\*.mp [23]
- 3/ photoelicitation\*.mp [7]
- 4/ photo-elicitation\*.mp [196]
- 5/ visual narrative\*.mp [63]
- 6/ body map\*.mp [306]
- 7/ ethnodrama\*.mp [11]
- 8/ exp psychodrama/ [2953]
- 9/ exp Drama/ [1899]
- 10/ ethnotheatre\*.mp [1]
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- 13/ reader\$s theater\*.mp [13]
- 14/ collage\*.mp [229747]
- 15/ portrait\*.mp [51387]
- 16/ art\$-based research\*.mp [38]
- 17/ art\$-based inquir\*.mp [3]
- 18/ art\$-inform research\*.mp [0]
- 19/ art\$-inform inquir\*.mp [0]
- 20/ or/1-19 [286923]
  
- 21/ exp Health Services Research/ [154600]
- 22/ 20 and 21 [350]
- 23/ limit 22 to yr="2009 -Current" [231]
- 24/ limit 23 to (English language) [222]

## Part B: Screening and Selection Process



**Figure 1: PRISMA Flow Diagram**

Source: Adapted from Moher et al. (2009)

### Part C: Descriptive Characteristics of Included Studies

Author Year	Country	Topic	Setting	Research Objectives
Angelo 2015	New Zealand	Caregiving	Home	Explore family caregivers' experiences from their perspective as they cared for dying relatives
Balbale 2014	United States	Patient-centered care and the experiences of healthcare workers	Veterans Affairs	Explore the perceptions and experiences related to patient-centered care among veterans receiving care in Veterans Affairs facilities that have implemented patient-centered care initiatives. In particular (1) understand how patients conceptualize patient-centered care, (2) examine the contextual elements that drive these perspectives, (3) assess the benefits of using photovoice to explore the perceptions of patient-centered care
Balbale 2015	United States	Patient-centered care	Veterans Affairs	Use photovoice to evaluate perceptions and experiences around patient-centered care among US Veterans Affairs health care employees
Cabassa 2012	United States	Health and well-being	Supportive housing agencies	Engage consumers with serious mental illness to inform the implementation of health care interventions
Cabassa 2013	United States	Recovery/adjustment	Supportive housing agencies	Explore how individuals with serious mental illness and a history of substance abuse and homelessness was applied to examine how the interrelationships between recovery dimensions support consumers' recovery journeys
Clements 2012	Canada	Recovery/adjustment	Community rehabilitation center	The goals of the Our Photos Our Voices project were to pilot a participatory action research and photovoice project, to facilitate discussions about recovery based

				on personal, local experience, and to produce a platform for sharing that local knowledge about recovery with others
Daniels 2017	United States	Recovery/adjustment	Community	Present an adaptation of photovoice with men-who-have-sex-with-men with HIV infection who live in Mpumalanga, South Africa. Our guiding research question was: What social factors influence HIV care decision-making for gay and bisexual men from the initial HIV diagnosis through engagement in care? We present photo essays that describe a shared experience involving HIV illness and coming to terms with having HIV, including the positive roles of families and taverns in their lives.
Davtyan 2016	United States	HIV-related stigma	Community HIV treatment center	Examine personal HIV-stigma experiences in Latina/Hispanic and African American women using Photovoice
Garner 2014	United States	Caregiving	Home	This study used a community-based participatory action research methodology called photovoice to explore challenges and supports experienced by family caregivers of the older adult
Graham-Pole 2009	Canada	Caregiving	Home	Our four objectives were to: (1) elicit information about caregivers' use of art in care; (2) explore its social and cultural contexts; (3) explore its benefits for caregivers and recipients; and (4) identify cross- and intra-cultural commonalities and differences.
Guerra 2012	Portugal	Caregiving	Home	Describe the evaluation of proFamilies-dementia, a program develops to support families that care for a relative with dementia using photovoice

Helm 2015	Hawaii	Drug prevention	Community	Conduct a community-university participatory action research project to develop a Native Hawaiian model of drug prevention
Horsfall 2012	Australia	Caregiving	Hospice	Illuminate the quality and effect of informal caring networks that are established, or strengthened, as a result of caring for a person dying at home; understand how being involved in such a caring network impacts family, friends and the wider community
Hunter 2011	United States	Chronic disease management and caregiving	Community	Used artistic means to enable community members to portray their experiences with chronic disease as a means to increase awareness of minority health
Ives 2015	United States	Chronic disease management	Community	Understand the needs and experiences of people living with diabetes, other comorbid chronic illnesses and vision loss in East Harlem
Kellehear 2009	United Kingdom	Factors relating to the physical healthcare environment	Hospice	Conduct a descriptive census of the personal possessions that patients bring to one hospice in the UK; examine how these objects act to personalize their inpatient environment
Kim 2017	South Korea	Caregiving	Home	Investigate Korean mothers' lives postdiagnosis of their child with cancer
LaDonna 2015	Canada	Chronic disease management	Community	Using photovoice to explore nine patients' experiences of living with myotonic dystrophy
Loignon 2015	Canada	Healthcare access and the experiences of healthcare	Primary care clinic	Combines the perspectives of persons living in poverty and of healthcare providers to explore barriers to responsive care for underserved persons with a view to

		workers		developing equity-focused primary care
Lorenz 2009	United States	Chronic disease management	Community	Show how providing cameras to patients and community residents can be effective at involving the public in generating understanding of consumer, community, and health system problems and strengths
Manning 2014	United Kingdom	Chronic disease management	Hospital	Explore and understand psychosocial well-being and needs of critical illness survivors, 6-20 months post-pediatric intensive care admission
Mizock 2014	United States	Recovery/adjustment	Rehabilitation center	Explore the meaning of recovery for individuals with serious mental illness based on a new photovoice-based intervention called Recovery Narrative Photovoice
Moore 2013	United Kingdom	Factors relating to the physical healthcare environment	Hospice	Explore experiences of the hospice as a place and how these changed overtime
Mosavel 2010	United States	Recovery/adjustment	Community	Understand the barriers and challenges that African American cancer survivors experience after being diagnosed with cancer
Musoke 2015	Uganda	Maternal health	Community	Explores community-level barriers affecting maternal health
Panazzola 2013	Canada	Recovery/adjustment	Community	Examine mental health issues of rural senior women and factors that negatively and/or positively affect their mental health
Parke 2012	Canada	Recovery/adjustment	Hospital	Identify the factors that facilitate or impede safe transitional care in the emergency department for

				community-dwelling older adults with dementia and to identify solutions that would support RNs' roles to provide gerontologically sensitive care
Peters 2017	Australia	Chronic disease management	Community	The goal of this participatory user research study was to explore the experience, needs, and ideas of young people with asthma while allowing them to define requirements for an asthma app that would be engaging and effective at improving their well-being.
Rani 2017	India	Healthcare access	Community	Understand the barriers and promoters to accessing eye care in rural communities
Rosen 2011	United States	Recovery/adjustment	Community methadone clinics	Understand the factors that enable older-adult African American methadone clients to enter and continue treatment
Satink 2015	Netherlands	Chronic disease management	Community	Explore the reflections of persons post-stroke on self-management, readiness and needs in self-management support
Sitvast 2010	Netherlands	Recovery/adjustment	Specialized mental health hospitals	Describe the role of facades in the process of suffering and acceptance
Speechley 2015	Canada	Chronic disease management	Community	Develop a theater script derived from a critical ethnographic study that followed people living with dementia and their family and professional caregivers
Tang 2016	Hong Kong	Healthcare access	Community	Explore the experience and impact of user participation in mental health services in Hong Kong through photovoice; examine the effects of this method in studying user participation

Tanner 2014	United States	Factors relating to the physical healthcare environment	HIV Clinics	To examine the elements and approaches to clinical “youth friendliness” with the primary objective to assess how staff constructed the notion of, and worked to improve, youth friendliness within clinics serving HIV-infected adolescents
Tishelman 2016	Sweden	Factors relating to the physical healthcare environment	Hospice	Understand which aspects of their surroundings are particularly meaningful for the people inhabiting them in the last phases of life, using an approach based on participant-produced photographs
True 2015	United States	Intervention design and evaluation	Veterans Affairs	Generate dialogue between veterans, health services researchers, health care providers, and organizational leadership that will inform the design of effective interventions to improve delivery of mental health care to veterans
Water 2017	New Zealand	Factors relating to the physical healthcare environment	Outpatient community clinics	Find out from children what they thought about the outpatient environment
Wells 2012	United Kingdom	Healthcare access	Hospital	Explore the lived experiences of adolescents with established renal failure undergoing dialysis and identify potential barriers to effective treatment
Wheeler 2018	United States	Chronic disease management	Hospitals and support groups	Gain a richer understanding of the perceived biopsychosocial and socioecological factors that impact quality of life for adults living with Crouzan syndrome using Photovoice; develop a conceptual framework of quality of life for those experiencing Crouzan syndrome to enhance tailored health education and services

Wilkin 2010	Australia	Experiences of healthcare workers	Hospitals	Use photovoice to understand the experiences of Aboriginal Health Workers
Woith 2014	Russia	Experiences of healthcare workers	Hospitals	(1) Determine the feasibility of conducting a larger scale study, and (2) test effectiveness of a photovoice intervention for changing attitudes and behaviors of Russian healthcare workers with regard to following protocols

### Part D: Methodological Characteristics of Included Studies

Author Year	Methodology/Analytic Approach	Type of ABHSR Method	Number and Type of Participants
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Angelo 2015	Narrative inquiry	Photovoice	10 family caregivers
Balbale 2014	Not reported	Photovoice	22 veteran patients
Balbale 2015	Not reported	Photovoice	12 healthcare workers
Cabassa 2012	Qualitative description	Photoelicitation	16 individuals with serious mental illness
Cabassa 2013	Grounded theory	Photovoice	16 individuals with serious mental illness
Clements 2012	Not reported	Photovoice	6 with mental health issues
Daniels 2017	Thematic analysis and adapted approaches	Photovoice	35 men-who-have-sex-with-men with HIV infection
Davtyan 2016	Phenomenology	Photovoice	10 African-American and Latina/Hispanic women with HIV
Garner 2014	Thematic analysis and adapted approaches	Photovoice	5 family caregivers
Graham-Pole 2009	Thematic analysis and adapted approaches	Multiple: appreciative inquiry	6 family or professional caregivers and 9 artists
Guerra 2012	Thematic analysis and adapted approaches	Photovoice	6 individuals from 5 families participating in the intervention
Helm 2015	Participatory action research	Photovoice	10 youth with demonstrated leadership in drug prevention
Horsfall 2012	Not reported	Photovoice	94 primary carers and mentors in the hospice
Hunter 2011	Not reported	Photovoice	24 African-Americans with a chronic disease
Ives 2015	Not reported	Photovoice	Four Latina/Hispanic women with a chronic disease
Kellehear 2009	Qualitative description	Photovoice	31 patients in a hospice
Kim 2017	Constant comparative method	Photovoice	4 mothers of children with cancer
LaDonna 2015	Constant comparative method	Photovoice	9 patients with myotonic dystrophy
Loignon 2015	Participatory action research	Photovoice	15 healthcare professionals (clinicians and administrators) and 6 members of a community organization
Lorenz 2009	Participatory action research	Photovoice	8 patients with an acquired brain

			injury
Manning 2014	Narrative inquiry	Multiple: interviews, drawings, paintings, photography, and collage	20 childhood critical illness survivors and 60 family members or healthcare professionals
Mizock 2014	Iconic visual anthropology analysis	Photovoice	20 patients with serious mental illness
Moore 2013	Phenomenology	Photoelicitation	11 patients in a hospice
Mosavel 2010	Grounded theory	Photovoice	20 survivors of cancer
Musoke 2015	Thematic analysis and adapted approaches	Photovoice	10 youth with perspectives on barriers to maternal health
Panazzola 2013	Not reported	Photovoice	31 senior women living in rural and remote areas
Parke 2012	Interpretive description	Multiple: Photoelicitation and photographic narrative journal	6 family caregivers, 10 nurses, and 4 nurse practitioners
Peters 2017	Thematic analysis and adapted approaches	Multiple: participatory design workbook and artifact collection	20 youth with asthma
Rani 2017	Not reported	Photovoice	15 members of paramedic team and 60 community members from 4 villages accessing eye care
Rosen 2011	Thematic analysis and adapted approaches	Photovoice	10 adults in a methadone maintenance program
Satink 2015	Constant comparative method	Photoelicitation	16 stroke survivors living in their communities
Sitvast 2010	Hermeneutic analysis and adapted approaches	Photoelicitation	NR
Speechley 2015	Ethnography	Performance inquiry (theatre and film)	NR
Tang 2016	Thematic analysis and adapted approaches	Photovoice	2 peer researchers and 3 patients who access mental health services
Tanner 2014	Constant comparative method	Visual narrative methods	124 healthcare professionals (clinicians, outreach workers, and

			administrators)
Tishelman 2016	Constant comparative method	Photoelicitation	23 patients in a hospice
True 2015	Not reported	Photovoice	29 veteran patients
Water 2017	Thematic analysis and adapted approaches	Multiple: draw and tell and letter writing	175 children attending outpatient clinics of hospitals
Wells 2012	Thematic analysis and adapted approaches	Photoelicitation	10 adolescents receiving renal replacement therapy
Wheeler 2018	Phenomenology	Photovoice	9 adults with Crouzon Syndrome
Wilkin 2010	Not reported	Photovoice	7 Aboriginal women
Woith 2014	Not reported	Photovoice	20 healthcare workers

## Part E: Summary Statistics

### Country

The majority of studies were conducted in the United States (16; 38.1%) (17-20,22-24,29,31,36,38,41,47,52,54,57), and Canada (7; 16.7%) (21,25,34,35,43,44,50). The remaining studies were conducted in the United Kingdom (4; 9.5%) (32,37,39,56); Australia (3; 7.1%) (28,45,58); New Zealand (4; 4.8%) (16,55); Netherlands (4; 4.8%) (48,49); Portugal (1; 2.4%) (26); Hawaii (1; 2.4%) (27); South Korea (1; 2.4%) (33); Uganda (1; 2.4%) (42); India (1; 2.4%) (46); Hong Kong (1; 2.4%) (51); Sweden (1; 2.4%) (53); and Russia (1; 2.4%) (59).

### ABHSR Methods

The majority of included studies identified with photovoice as their primary ABHSR methodology and approach (29; 69.0%) (16-18,20-24,26-29,31-36,38,41-43,46,47,51,54,57-59). The second most common was photo-elicitation methods (6; 14.3%) (19,39,48,49,53,56). One (2.4%) study used performance inquiry such as theater and film (50), and another study (2.4%) used a visual narrative method different from photovoice and photoelicitation (52). Five (11.9%) studies used multiple methods: appreciative inquiry (25); photographic narrative journal and photo-elicitation (44); interviews, drawings, paintings, photographs, and collage (37); participatory design workbook and artifacts (45); and draw and tell, letter writing, and interviews (55).

### Qualitative Methodology or Analytic Approaches

In total, 31 (73.8%) studies identified a particular qualitative methodology or analytic approach and 11 (26.2%) did not (17,18,21,28,29,31,43,46,54,58,59). Of included studies that identified with a methodology or approach, the most common was thematic analysis and adapted approaches (10 studies; 23.8%) (22,24-26,42,45,47,51,55,56), followed by constant comparative method (4 studies; 9.5%) (33,48,52,53), phenomenology (3 studies; 7.1%) (23,39,57), participatory action research (3 studies; 7.1%) (27,35,36), qualitative description (2 studies; 4.8%) (19,32), grounded theory (2 studies; 4.8%) (20,41), and narrative inquiry (2 studies; 4.8%) (16,37). One of each of the remaining studies identified with content analysis (34), iconic visual anthropology analysis (38), interpretive description (44), hermeneutic analysis and adapted approaches (49), and ethnography (50).

### Research Topics and Objectives

A thematic inductive analysis was performed to classify included studies on a range of topics that are relevant to HSR. The most common topics were recovery/adjustment process (9; 21.4%) (20-22,38,41,43,44,47,49); chronic disease management (9; 21.4%) (29,31,34,36,37,45,48,50,57); and caregiving (8; 19.0%) (16,24,25,26,28,29,33,50). Other topics were factors related to the physical healthcare environment (5 studies; 11.9%) (32,39,52,53,55); healthcare access (5 studies; 11.9%) (35,42,46,51,56); intervention design and evaluation (5 studies; 11.9%) (19,26,27,45,54); the experiences of healthcare workers (4 studies; 9.5%) (18,35,58,59); and patient-centered care (2 studies; 4.8%) (17,18). More details regarding specific subtopics of included studies are shown in Table 4.

Table 4: Topics and subtopic of included studies

<b>Recovery/adjustment process</b>	<ul style="list-style-type: none"> <li>• The role of homelessness and substance abuse on recovery (20)</li> <li>• The factors that influence patients' access to methadone clinics (47)</li> <li>• How to support dialogue about recovery in patients with mental health issues (21)</li> <li>• The mental health needs of patients (43,49)</li> <li>• Factors that affect how individuals understand and adjust to an HIV infection (22)</li> <li>• Examine HIV-related stigma (23)</li> <li>• The meaning of recovery for those with a serious mental illness (38)</li> <li>• The barriers and challenges patients face after being diagnosed with cancer (41)</li> <li>• The barriers and facilitators of transitional care in emergency department (44)</li> </ul>
<b>Chronic disease management</b>	<ul style="list-style-type: none"> <li>• Experiences and awareness of chronic disease and its management (29)</li> <li>• Living with dementia, diabetes, myotonic dystrophy, asthma, stroke and other comorbid conditions (31,34,45,48,50)</li> <li>• Consumer, community, and health system problems and strengths (36)</li> <li>• Psychosocial well-being and needs of survivors of cancer (37)</li> <li>• Understanding the narratives of people living with dementia and their caregivers (50)</li> <li>• The quality of life of children living with Crouzon Syndrome (57)</li> </ul>
<b>Caregiving</b>	<ul style="list-style-type: none"> <li>• Perspectives and experiences of caregivers who are caring for a dying relative (16)</li> <li>• Challenges and supports experienced by family caregivers (24)</li> <li>• The advantages of using art to understand the perspectives and experiences of caregivers (25)</li> <li>• Describe the evaluation of a dementia program (26)</li> <li>• The influence of caregiving networks on health and wellness on caregivers (28)</li> <li>• The lives of mothers after diagnosis of child with cancer (33)</li> <li>• Understanding the narratives of people living with dementia and their caregivers (50)</li> </ul>
<b>Factors relating to the physical healthcare environment</b>	<ul style="list-style-type: none"> <li>• Personalization with environment and bringing possessions to hospitals for in-patient care (32)</li> <li>• How experiences with hospice as a place to spend the last days of life evolved overtime (39)</li> <li>• The characteristics of clinics that make it a youth-friendly environment (52,55)</li> <li>• Aspects of the physical environment perceived as most</li> </ul>

	meaningful to dying (53)
<b>Healthcare access</b>	<ul style="list-style-type: none"> <li>• Barriers to responsive care for underserved persons (i.e., those who are poor) (35)</li> <li>• Community-level barriers that affect maternal health access (42)</li> <li>• Barriers and facilitators to accessing eye care in rural communities (46)</li> <li>• The impact of patient engagement on mental health services (51)</li> <li>• Barriers to renal replacement therapy in adolescents (56)</li> </ul>
<b>Intervention design and evaluation</b>	<ul style="list-style-type: none"> <li>• Engaging consumers in the design and implementation of mental health interventions (19,54)</li> <li>• Describe the evaluation of a dementia program (26)</li> <li>• Developing a model for drug prevention in a community (27)</li> <li>• Development of an asthma app for youth (45)</li> </ul>
<b>Experiences of healthcare workers</b>	<ul style="list-style-type: none"> <li>• Barriers to responsive care for underserved persons (i.e., those who are poor) (35)</li> <li>• Healthcare workers' experiences with patient-centered care in the Veterans' Affairs (18)</li> <li>• The experiences of Aboriginal healthcare workers (58)</li> <li>• Experiences of healthcare workers who were involved in a feasibility study using an arts-based HSR approach (59).</li> </ul>
<b>Patient-centered care</b>	<ul style="list-style-type: none"> <li>• Experiences of veterans in institutions with patient-centered care initiatives (17)</li> <li>• Healthcare workers' experiences with patient-centered care in the Veterans' Affairs (18)</li> </ul>