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'The healthcare system is not designed around my needs': How healthcare consumers self-integrate conventional and complementary healthcare services

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ABSTRACT

Objective: To explore healthcare consumers' experiences of healthcare service integration.
Methods: This phenomenological study comprised three focus groups of 13 participants who were purposively invited to span three broad generations: young adults, middle-aged adults and seniors. Transcripts of focus group recordings were analysed thematically.
Results: Key themes were that: (i) healthcare consumers manage their own healthcare, (ii) healthcare consumers value open, non-judgmental communication with healthcare providers, and (iii) healthcare consumers want flexibility in healthcare services.
Conclusions: Healthcare consumers integrated their own healthcare, including complementary and alternative medicine (CAM) and conventional medicine, by researching practitioners and services and by engaging in service and product rating strategies. They moulded available health services around their needs. Without the support of healthcare providers, healthcare integration, knowledge exchange and risk management are limited. A system of healthcare integration that omits CAM fails to meet community needs, policy aims for greater efficiency, and duty of care to healthcare consumers.

1. Introduction

As the burden of healthcare moves from infectious to chronic diseases globally, there is an increasing pressure on health systems to adapt. More than 50% of the current global healthcare burden can be accounted for by diabetes, depression, cardiovascular disease and disabilities [1]. In addition, health systems are under increasing pressure to consider healthcare consumers' access and satisfaction with service provision. The World Health Organisation identified responsiveness to healthcare consumers' expectations as one of three key performance indicators to measure the quality of health systems [2]. Responsiveness to healthcare consumers' expectations requires that they are consulted, treated as partners in their healthcare and entitled to choose their own healthcare providers. Integrating health services and working towards continuity of care to achieve person-centred healthcare has been consistently endorsed as the most ethical and efficient pathway towards health systems reform [3].

A somewhat inconvenient truth about consumers' preferences for healthcare in many Western countries is the rising prevalence of CAM use. The Australian Health Survey (2011–12) [4] estimated that 9.3% of the general population had consulted one of six specified complementary health practitioners within the previous 12 months, but this prevalence was around 13% for the age categories between 25 and 65 years. An earlier National Health Survey (2004–5) estimated that 3.8% of the Australian population (n = 748,000) had consulted one of seven selected natural or complementary therapists within the two weeks prior to the survey, which was up from 2.8% in 1995 [5]. This rising use of CAM health services in Australia raises a number of concerns about health outcomes for consumers. For example, reports of non-evidence based CAM being used in place of evidence-based treatments for healthcare consumers with chronic conditions continue to cause unease among Australian health authorities [6]. Other concerns about CAM include their efficacy, potential interactions with medically-prescribed treatments and financial cost to the community [7].

These concerns do not deter CAM consumers. Findings from a national, representative sample in the US reported that 79% of healthcare consumers who used both CAM and conventional medicine perceived the combination to be superior [8]. This is consistent with findings from an interpretive study that examined consumers' experiences of integrative medicine in Australia [9]. Both healthcare consumers and

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practitioners in this study reported that combining CAM and conventional medicine provided healthcare that was more effective in managing their health needs than either CAM or conventional medicine alone. Evidence that only 50% of CAM consumers report their CAM use to their general medical practitioners (GPs) [10] increases the probability of adverse events due to the interaction of specific combinations of pharmaceuticals and CAM treatments. This raises concerns about the safe integration of CAM at the level of primary healthcare. A better understanding of the drivers of these behaviours may be an important step forward in planning models of person-centred healthcare integration and communication.

Approaches to integrated healthcare service delivery models are being explored to respond to the high cost of healthcare and quality gaps in healthcare [11]. Healthcare integration can occur at different stages of care (e.g. between the local community and hospital services) and between networks and groups at the same stage of care (e.g. primary healthcare) [12]. Integrated care pathways need to incorporate all aspects of healthcare consumers' care at every stage and follow them across healthcare providers and organizational boundaries [13]. However, existing models of integration still largely ignore the consumer [14] and the widespread use of CAM. The aim of the research was to consult healthcare consumers about their experiences of healthcare service delivery, with particular regard to their integration of CAM and conventional medicine practitioner/service use.

2. Material and methods

2.1. Study design and participants

The study was part of a larger body of work investigating healthcare consumer integration of CAM with conventional medicine. This aspect of the research consisted of a phenomenological study to explore consumers' experiences of healthcare services. Phenomenology focuses on subjective experiences and personal meanings constructed from the experiences of everyday life 'constituted by the thoughts and acts of individuals and the social expressions of those thoughts and acts' p.83 [15]. In this study a descriptive phenomenological approach was appropriate to uncover the 'universal essence' of the experience as reported by study participants [16]. In descriptive phenomenology researchers attempt to put aside or bracket their personal preconceptions and biases so that the essence of the experience can emerge [17]. This was important because the researchers were all experienced complementary medicine practitioners. Their interest in the project stemmed from observations of the ways in which their own patients managed two parallel health systems. Focus groups were designed to understand the most important issues that arise for healthcare consumers when they are managing CAM with conventional medicine services. This understanding informed the design of an online survey that will be reported in a subsequent publication. The research had the approval of the institutional Human Research Ethics Committee (ECN-16-250).

Three purposive focus groups were recruited to span three broad generations (young adults, middle-aged and older adults). Participants were Australian adults who identified as consumers of both conventional medicine and CAM services. The participants were recruited from a database created from a previous survey called 'Patient Perceptions of Integration', personal and professional networks and a Facebook page created to engage consumers of CAM services [14]. Those who agreed to participate were given a Participant Information Sheet that provided details of the study and signed the Informed Consent form.

Focus groups were conducted face to face by one of the researchers either on the university campus or at a location convenient to participants. Two groups had four participants each and one had five. Each group lasted approximately 1 hour. The questions were designed to facilitate discussions about participants' experiences of the healthcare system, particularly in regard to integrating their total healthcare, including CAM (see Appendix A). The focus groups were digitally recorded with participants' consent and transcribed verbatim.

2.2. Data analysis

Data analysis was informed by Colaizzi's five step method where researchers attempt to understand the meaning of participants' experiences through their descriptions [18]. Transcripts were read and reread independently by each of the researchers, initially to 'acquire a sense of the transcript', and then to 'extract significant statements'. Next, the researchers attempted to 'formulate meanings' for each significant statement. The four members of the research team met on two occasions to discuss, refine, coalesce and discard formulated meanings, maintaining close engagement with the data until 'clusters of themes' were identified and agreed upon. No further focus groups were required as consistent major themes emerged. These themes were considered sufficiently rich to inform the subsequent phase of the research project. In the final stage the phenomenon under investigation was 'exhaustively described', that is reported in such a way that it all emergent themes, clusters and formulated meanings were described.

2.3. Quality criteria

This research was guided by the quality criteria for qualitative research described by Kitto et al. [19]: (1) justification for using phenomenological research, (2) procedural rigour, (3) representativeness, (4) interpretation, (5) reflexivity and evaluative rigour, and (6) transferability. All of these criteria have been addressed. In addition, the Consolidated Criteria for Reporting Qualitative research (COREQ) checklist [20] was used to guide the reporting of this research. The credibility of the results was confirmed by prolonged engagement with the data, the use of four researchers who conducted independent analyses, and feedback from two participants following review of the findings.

3. Results

3.1. Participant demographics

A total of 13 people participated in the three focus groups. Table 1 is a summary of participant demographics.

3.2. Major themes

Three major themes emerged from the data: i) healthcare consumers self-manage their healthcare integration, (ii) healthcare consumers value open and non-judgmental communication with practitioners, and (iii) healthcare consumers want flexibility in healthcare services, particularly in relation to the integration of CAM and conventional medicine.

Table 1
Demographics of participants in three focus groups.

Participant	Gender	Age (Years)	Chronic Health Condition?
1	Female	77	Yes
2	Female	75	Yes
3	Male	76	Yes
4	Male	81	Yes
5	Female	28	Yes
6	Female	29	No
7	Male	34	Yes
8	Female	29	No
9	Female	28	No
10	Female	34	Yes
11	Female	51	Yes
12	Male	28	No
13	Male	51	No