

Client Participation and Health Education in Community: A Scoping Review

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ABSTRACT

While the contemporary healthcare systems recognize the effectiveness of a collaborative approach to delivering care, client participation has been considered as an essential component to person-centered healthcare. The purpose of this paper is to examine the definitions of client participation, describe the benefits of client participation in community health education, examine the factors that influence client participation, and discuss strategies to promote client participation. Client participation has been found to improve health outcomes, increase client satisfaction, and reduce healthcare-related costs. Factors that may influence participation are socioeconomic status, clients' perceptions of their roles, and healthcare bias or behaviour. Strategies that promote client participation include establishment of a framework or set of guidelines, proactive outreach to increase provider accountability, use of diverse media to improve knowledge translation, and training healthcare professionals.

Keywords

Client participation, Health education, Community, Literature, Review.

Introduction

In the past there were expectations for clients to be compliant with the directives of health professionals, with limited opportunities to participate in decision-making processes. Coinciding with the current definition of health as complete physical, mental, and social well-being, the World Health Organization (WHO) recommends client participation at all levels of healthcare to empower clients [1,2]. This holistic stance to healthcare acknowledges that clients have health priorities and goals unique to themselves, and that supporting them in finding meaning within their lived experiences will ultimately lead to better health outcomes [2]. Consequently, healthcare providers are tasked to treat whole persons, and not just disease components. Healthcare providers can no longer rely solely on treating the physiology of a disease as complete client

care, but must also incorporate achieving health outcomes that are meaningful to clients themselves [2]. Healthcare providers, administrators, and policy makers are encouraged to support and champion their clients to be active in their care, such as managing their personal conditions and risk factors, adhering to treatment, and participating in clinical decisions [1]. The WHO further calls upon whole communities to contribute towards healthy environments by exerting their rights and responsibilities, participating in the development of health policies, understanding options available to the community, and making health-related decisions that best meet the community's needs [1].

Client participation is a concept that is historically rooted in social development, with interests in the community, the public, and at the citizen level [3]. The seminal framework of this approach, the Ladder of Participation [4] highlights different magnitudes of participation at the micro, meso, and macro levels [3]. This resilient framework has since been explored within the healthcare context, particularly in alignment with social and behavioural

theory. It proposes that health behaviours are influenced by social and contextual factors that can collectively be called *Social Determinants* [5]. Client participation, can therefore be encouraged within diverse settings, at the levels of individual care, service development, planning, delivery, evaluation of care, and policy [3]. The purpose of this paper is to define client participation and explore the benefits of promoting client participation at the individual and community level in health education. Furthermore, this paper will also seek to examine the factors that influence client participation. Finally, a discussion on strategies that promote client participation will be highlighted.

Methods

Literature searches on client participation and health education in community were conducted in various databases included MEDLINE, ERIC, ProQuest, PsycINFO, and CINAHL. The used searching keywords were “client participation”, “patient participation”, “client involvement”, “patient involvement”, “patient empowerment”, “patient-centered”, “patient-oriented”, “community”, “health education”, “health teaching”, and “health learning”. Inclusion criteria are: articles were (a) written in English, (b) focused on the related issues of client participation, and (c) related to health education in community. Due to the limited literature on this topic, articles from any year and discipline were included in this review. Exclusion criteria are: articles (a) did not have an accessible electronic text document, or (b) did not have an author, or (c) were review paper, or (d) were commentary. In total, 20 papers met the criteria and were selected for this review.

We used Critical Appraisal Skills Program Checklists as quality assessment tools to assess included articles [6]. These checklists are designed to evaluate the studies as a whole, classifying their quality as low, moderate or high. Two researchers independently evaluated each article; any discrepancies in ratings were discussed along with the guidelines until a consensus was reached. We only included papers that were rated at moderate to high quality. We extracted individual details of the included studies such as authors, year of publication, study population, research design, and significant findings.

Definition and Measurement of Participation

International recognition of the concept of participation was demonstrated when the WHO promoted it as a central tenet for health policy in its 1978 Declaration of Alma-Ata, stating that people have a right and duty to participate individually and collectively in the planning and implementation of their health care [7]. The first framework of participation was brought forth by Arnstein who proposed eight levels of participation in her highly distinguished Ladder of Participation. Arnstein’s model uses a ladder as a metaphor to portray the gradations of people’s participation in matters that affect their lives [3]. Following from the least to most empowering, the levels are: manipulation, therapy, informing, consultation, placation, partnership, delegated power, and citizen control [8].

At the lowest rungs of the ladder are manipulation and therapy, two

forms of nonparticipation that disingenuously seek participants when there is already a predetermined course of action [9]. Citizens are led to believe that they are participating in the decision-making process, but they serve in more of a figurehead role, holding no influence over the course of planning or implementation. Examples of this approach include lectures, handouts, and pamphlets [9] where information flow is unidirectional.

The levels of informing, consultation, and placation in Arnstein’s ladder allow information to be exchanged between the participants and the decision-makers, but are flawed due to the absence of accountability. Surveys, for example, may provide insight on participants’ satisfaction or dissatisfaction with the services or programs offered to them, but rarely have follow-through to ensure that their input leads to actual change [9]. There is no guarantee that decision-makers will see all the feedback that they receive or personally address the concerns of every participant; as such, participation that does occur is immediately devalued or trivialized.

Partnership, delegated power, and citizen control comprise the highest rungs of Arnstein’s ladder [9]. At these levels, participants are enabled to negotiate and engage in quid pro quo with traditional power holders to obtain the majority of decision-making positions and full managerial power over the mobilization of resources [4]. Arnstein posits that devolving control of the decision-making process to participants that are empowered by partnership, delegated power, or citizen control leads to the best outcomes.

The definitions surrounding client participation in the healthcare context vary considerably and conceptual clarification is required to facilitate communication between all stakeholders. ‘Client participation’, ‘client empowerment’, and ‘client centred’ are prominent terms that have been used interchangeably in research literature over the last three decades [8]. Client-centredness largely describes the quality of a relationship between a client and a healthcare professional, with particular attention to empathy. Client empowerment is less related to healthcare and instead emphasizes the process through which individuals take responsibility for their own health. Client participation involves active engagement in the healthcare community at the collective level, mutual partnership with healthcare providers, and informed decision-making with regards to their individual health [8].

Far from being mutually exclusive, these perspectives reveal a synergistic interrelationship that exists across a client’s continuity of care. Specifically, client empowerment is a meta-paradigm, client participation is a strategy to achieve client-centered care, and a client-centered approaches in turn lead to client empowerment [3]. Drawing from these interpretations, client participation in health education will encompass, the process in which clients and their healthcare providers collaborate together to make informed decisions regarding the clients’ own health. The concept of client participation will be explored at different levels within the healthcare context, these levels include the micro, which focuses on individual care; meso, such as service development, planning, delivery and evaluation of care, and education and training of

health care providers; and macro at the policy level [3].

It is important to identify a standardized tool to measure client participation as Arnstein's ladder has indicated that it is not simply a matter of whether or not aspects of participation exist, but that there is a spectrum of levels to participation that needs to be explored [3].

The Patient Activation Measure (PAM) is a valid, highly reliable, unidimensional, probabilistic Guttman-like scale that conceptualizes the stages of client participation and engagement using psychometric properties [10]. It assesses four stages in the client: (1) believing the client role is important, (2) having the confidence and knowledge necessary to take action, (3) actually taking action to maintain and improve one's health, and (4) staying the course even under stress [10]. A higher score on this tool indicates that a client is highly participatory and likely to meet most, if not all, of the aforementioned stages. Higher scores further suggest that higher rungs of Arnstein's ladder of participation are being facilitated [3]. A recent study suggested that PAM can be used to adequately explore clinicians' attitudes and beliefs regarding client self-management [11]. Information about clients' perspectives on engagement reveal their lived experiences and the extent of care provided by healthcare providers, which aid in future decision making.

Benefits of client participation in health education

Benefits of client participation in health education include improved health outcomes, increased client satisfaction, and cost effectiveness.

Improves Health Outcomes

There is increasing evidence that client participation contributes to the development of better health outcomes. In the dynamic therapeutic relationship, clients and health providers should share relevant healthcare information and resources so that clients can consider all the options available to them and decide on a plan of care that best suits their individual lifestyles, cultural beliefs, and personal values [11]. Participation is essential to enable clients or communities to increase their healthcare knowledge, improve their capacities to have control over their conditions, and produce better health outcomes. Cross-sectional and prospective studies, both domestic and international, have empirically demonstrated that clients with higher PAM scores were significantly more likely than those with lower PAM scores, to engage in preventative behavior. These preventative behaviours included eating a healthy diet, getting regular exercise, having regular check-ups, attending health screenings, receiving immunizations, and avoiding smoking and illegal drug use [12]. In studies involving clients living with chronic or life-long conditions such as diabetes and severe mental illnesses, higher PAM scores indicated higher likelihood that the client would adhere to treatment, perform self-care, keep a glucose diary, exercise regularly, and obtain regular foot exams [13]. Furthermore, highly engaged cardiovascular clients were more likely to have normal values in biometrics such as body mass index, hemoglobin A1c, blood pressure, and cholesterol

[12]. Clients with lower PAM scores were two to three times more likely to have unmet healthcare needs, delay healthcare, and attend medical appointments without questions about treatment guidelines. These findings were presented from studies of clients with a wide range of health conditions and economic backgrounds, and have been replicated in populations from Japan, Norway, the United Kingdom, and Australia [12].

Increased Client Satisfaction

Client participation over time contributes to a professional relationship between client and healthcare provider based on trust and transparency [14]. A good rapport is essential in improving the client experience and increasing client satisfaction as a recipient of healthcare [14]. A client may be more open to participate in open dialogue with his or her healthcare provider and provide feedback about their treatment options when they feel their opinions are valued by their healthcare providers [15]. In this case, clients will likely have the skills and confidence to elicit what they need from their providers. In particular, clients with chronic conditions and higher PAM scores reported fewer problems with treatment compliance and the coordination of care [12]. Higher-quality interpersonal exchanges with physicians, greater fairness, and more out-of-office contact with physicians were associated with higher PAM scores [12]. However, even though a correlation exists, most of the studies looking at client participation and client experience are cross-sectional, which makes interpreting the direction of causality difficult.

Cost Effectiveness

In recent times, evidence has shown that client participation does contribute to lower health care costs. The financial burden of healthcare costs has changed the role of clients, from traditionally seeking healthcare advice at any signs of alarm, to performing self-care in the comfort of their home. This transition where clients begin to take a more active role in decisions regarding their health, is facilitated by advancements in technology that make shared decision making easier for the client and increase the accessibility of health information [16]. In a study of more than 25,000 clients in a large health care delivery system in Minnesota, USA, it was found that every additional 10 points scored on the PAM correlated with a 1% decrease in the predicted probability of having an emergency department visit [12]. Hibbard and Greene published the first study that specifically examined client participation and billed health care costs. In their analysis of over 33,000 clients, it was found that clients with lower PAM scores had a predictive average cost that was 8% higher in the base year and 21% higher in the first 6 months of the next year [12]. As health care systems move toward more accountability for costs and health outcomes for defined client populations, supporting clients in taking active control over their own health is integral to the healthcare provider's ability to improve health outcomes and lower costs.

Factors Influencing Client Participation

Clients may face challenges during the participation process that could variably influence the length, frequency, or quality of their engagement at any point of time. Notable themes that are

consistently discussed in literature are autonomy and bioethics; socioeconomic status; client's perceptions of their role; and healthcare provider beliefs or behavior.

Socioeconomic Status

Socioeconomic status seems to affect healthcare provider's perceptions of their clients, which then guides their behavioural and communicative efforts with the client, often with negative consequences [17]. Physicians were found to modify their interviewing style according to their perception of the client's socioeconomic class. Clients believed to be in a lower class received more paternalistic, less participative healthcare consultations and were less likely to be invited by the healthcare provider to build a partnership. This came as a result of the practitioner's erroneous belief that less educated clients had less need for information and a lower capacity to participate in the decision-making process [17]. Similar findings were revealed in a qualitative study on physicians, which indicated that changes to clinical management were made in an effort to enhance client outcomes, but that physicians experienced numerous strains when trying to balance what they believed was feasible for the client with what they perceived as established standards of care [18]. Another study suggested that economic factors influenced the habits of African Americans cancer clients in seeking healthcare information. Limited monetary resources and lack of insurance coverage were viewed as contributing to delays in healthcare seeking [19]. Socioeconomic factors may influence client participation, with reference to how educational level may impact health literacy and a client's potential to think critically about their healthcare decisions [16].

Client's Perceptions of Their Role

Client participation must be prefaced by a belief that their input holds value and will lead to actual change. There exists a paradox plaguing client centred care in that clients are burdened with opportunities to voice their concerns. Clients and family members may fear that mentioning a problem will result in retaliation or poor care. Furthermore, it is often the reality that healthcare providers are unable to respond in real time when clients do choose to express a concern, reinforcing their belief that speaking up is not worth the effort and risk [20]. Hence, health care systems and providers must create an environment in which clients and family members feel safe raising concerns and are confident that their feedback will be welcome and enhance their care. To address such issues, it is imperative that participation adopt rigorous standards of transparency and accountability because without these, public involvement could undermine trust [7].

Healthcare professionals must identify their knowledge base to the client and support clients in understanding their own roles during participation [8,11]. This ensures that the client will ask relevant questions to the most appropriate healthcare providers. It would be inefficient, for example, to ask a sonographer about the side effects of a medication. This endeavour can be made more difficult by the lack of conceptual consensus on the meaning of 'client participation', the existence of language barriers, culturally insensitive care, distrust in the client-provider relationship,

bureaucratic inefficiencies, intolerant organizational policies, and more. Finset provided an example wherein new immigrants and seniors took initiative to obtain social support, seek health information, and participate in the health education sessions, despite experiencing social isolation due to culture and language barriers.

Williamson cautioned healthcare providers to be mindful of the confusion that could be created by the need for participants to assume different roles at different times depending on their interaction with the health care system. Healthcare providers must acknowledge that clients have different resources for health education that may have been sought outside of those offered by the provider. Thus, efforts must be made to articulate the aims of public engagement in a manner that avoids circumstances in which participants are not clear themselves, on which perspective to adopt in any given health care decision-making context [7]. These initiatives should be based on an explanation of the relationship between different information forums that clients may use.

Healthcare Provider Beliefs and Behaviour

Health care workers' beliefs, attitudes, and behavior can have a major effect on client participation [6,15]. As previously mentioned, socioeconomic status has been found to influence healthcare providers' perceptions of a client's participatory potential [17]. Further to this, health care workers can limit client participation by using authoritative language in the form of veiled orders ("you should," "it is necessary that", "it is best that") and condescending terms ("be good", "be cooperative"), regardless of whether or not this language is conscious [16]. Accusatory tones may also intimidate clients and deter them from seeking involvement in decision-making, as was in the case of a healthcare speaker who complained of clients being noncompliant with physicians' orders [20]. Clients should not be made to believe that it is their fault when treatment options fail [7]. It is important for healthcare providers to understand that a lack of evidence for success does not necessarily signify a lack of actual or potential benefit; rather, it could signify the need for additional research or improved involvement techniques or strategies [7].

Strategies to Promote Client Participation

Strategies to promote client participation are important in engaging clients. Strategies to improve client participation include Carman's Framework for Client and Family Engagement, proactive outreach, use of diverse media for knowledge translation, and training healthcare providers and educators.

Carman's Framework for Patient and Family Engagement:

Carman's Framework for Client and Family Engagement in Health and Health Care directs that client engagement should begin by incorporating clients' values, perspectives, preferences, and experience in disease prevention, diagnosis, and treatment. Supporting client engagement means that clients must be actively involved in care plans, communicate their goals, make shared decisions, and proactively manage their health. Moreover, healthcare providers must help clients to communicate, and to

understand and balance the risks and benefits of their healthcare choices. Healthcare providers must promptly give clients, as much information as possible to aid in their understanding, and must involve the family and support persons [21].

Proactive Outreach

Healthcare institutions and providers should use a proactive approach, rather than a reactive approach, in interviewing to encourage clients to discuss their experiences. Proactive outreach attempts to enable real-time responses by healthcare providers to concerns that clients report during their participation. An aspect of this approach is to identify “near misses” and remediate problems as they occur, thereby mitigating harms. This can be incorporated into existing processes such as healthcare manager rounds or assigning clients to a client advocate or ombudsman. Proactive outreach encourages client-initiated reporting and validates their concerns in a way that reactive approaches cannot. This in turn increases client satisfaction with their healthcare experiences, positively affects client’s perceptions of their roles in participation, and establishes rapport in the client-provider relationship to sustain participation [20].

Use of Diverse Media for Knowledge Translation

Use of diverse forms of media to improve knowledge translation can facilitate this gap in information exchange. Studies on client participation identify challenges due to the nature of the relationship between laypersons and professionals, and the embedded difference in situation and knowledge [22]. This difference may be reduced by active knowledge translation. For example, healthcare providers can develop a multimodal video and print campaign which can be deployed in reception areas and client rooms, which can then be proactively reinforced by all providers [20]. Such campaigns should include easy ways for clients to speak up via several well-publicized and accessible reporting channels to gain feedback. In addition, client engagement surveys can be used to improve identified areas of weakness in the healthcare system by encouraging appropriate organizational decisions. Such information can also be used to hold physicians and nurses accountable [21].

Train Healthcare Providers and Educators

As Williamson has indicated, changes in health policy could pave ways for client participation, but only at the macro levels [3]. In order for policy to be translated into actual care and reach its intended beneficiaries (the clients), it is pertinent to ensure that the mediators at the meso level (healthcare providers) have the healthcare knowledge and interpersonal skills necessary to sustainably support clients during the participation process. Thus, training healthcare providers on how to best engage their clients, regardless of health conditions, is a crucial step towards the realization of client participation in healthcare.

Esther Wojcicki’s T.R.I.C.K. concept can be employed by healthcare providers to build a sustainable, client-centered learning environment that promotes client participation [23]. The acronym of T.R.I.C.K. stands for trust, respect, independence, collaboration

and kindness [23]. It recommends that health educators build a foundation of trust with clients or communities, prior to educating them. Clients with high trust in their healthcare providers have been found to have improved health outcomes, improved chronic disease management, increased use of preventative services, and satisfaction with care [14]. To reach this goal, health educators should maintain their interpersonal and professional competence, demonstrate caring and personal knowing, and provide clients with effort, continuity, and time [14].

‘Empathetic partnership’ is an interdisciplinary framework for primary care practice for healthcare practitioners that fosters cultural safety and the embracing of vulnerabilities [24]. True to the meaning of ‘partnership’, health educators should allow clients or communities to conduct health promoting activities at their own pace and through independent agency. In this way, clients can establish their individual concerns and learning expectations, define their own success, and find meaning in their participation. In supporting this endeavour, health educators should respect clients or communities by actively listening to concerns, appreciating diverse backgrounds and cultures, demonstrating patience and accountability throughout the process, and providing feedback with understanding and empathy [24]. In this collaborative effort that emphasizes coaching and empowerment, authentic and effective health education can be achieved [24].

Training healthcare providers to hone their abilities to access and promote client participation remains a priority in healthcare education. In a pilot feasibility study where 46 nurses were trained to engage chronic clients in their healthcare journey, successful completion of the training program was found to change clinicians’ attitudes and expertise in promoting client participation [15]. Furthermore, professionals demonstrated an increase in confidence in their own ability to support their clients’ participation during the care process [15]. These findings would suggest that the information that a health provider gathers through client participation and engagement is a valuable resource that helps them better understand the multitude of factors that affect a client’s health outcomes. Client participation in health education provides an authentic opportunity in which participants and their health educators can constructively engage in an enriching dialogue that leverages the participant’s knowledge and the educators’ awareness of participants’ concerns.

Conclusion

The definition of client participation is based on core constructs of engagement, empathy and compassion, communication, self-management, and shared decision-making [3]. These constructs elude to the viability of client participation as a core strategy to empower clients and communities. The use of the concept of client participation encourages clients to shed their passive role and regain autonomy over their health through collaboration with healthcare providers and educators. Healthcare professionals and systems also benefit from client participation as the improved health outcomes will ultimately lead to reduced health-care related costs, improved relationships with clients, and a better understanding of the diverse

health priorities that exist in their client populations. Literature have also revealed that there remain contextual challenges which continue to prevent clients or communities from reaching their full capacities in health promotion and disease prevention.

More studies are required to understand the long-term effects of client participation and distinguish it as a process or a product. If client participation is considered a product, then its benefits will be quantitatively measured in terms of concrete outcomes as defined by healthcare providers; if it is a process, then a qualitative change is the desired outcome and benefits of client participation are defined uniquely by clients as a combination of factors from their learning experiences. Thus, while client participation is a viable strategy for client empowerment in health education, researchers, healthcare providers, healthcare educators, and policy makers must take care to apply the strategies not as a means to an end, but rather, as primary practice in contemporary healthcare.

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