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Viewpoint

The Participatory Zeitgeist in Health Care: It is Time for a Science of Participation

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Abstract

Participation in health care is currently the zeitgeist/spirit of our times. A myriad of practices characterizes this “participatory Zeitgeist” in contemporary health care, which range from patients and professionals collaborating as partners in service delivery and treatment decision-making, to crowdsourced cures and participation in online communities, to using health apps, to involvement in health care quality improvement initiatives for systems redesign using coproduction and co-design methods. To date, patient engagement and participation in online communities and the use of apps have received a good deal of attention in participatory medicine. However, there has been a less critical examination of participation in health care planning, design, delivery, and improvement. In the face of what Thomas Kuhn called a scientific revolution, we are presented with the opportunity to re-examine some of the assumptions underpinning participation in health care and some of the emerging anomalies and weaknesses in the current science. This re-examination will allow the development of a new paradigm, a science of participation. In this science, we can systematically test, refine, and advance participation in health care to build a unifying language and theories from across the interdisciplinary fields of participatory design, medicine, and research to develop and test models to explain impacts and outcomes. A science of participation will allow the emergent and unexplained facts to be addressed in the current participatory mood of health care planning, design, delivery, and improvement.

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KEYWORDS

participation; participatory methods; health care improvement; quality improvement; coproduction; co-design; theory of science

Introduction

Contemporary health care planning, design, delivery, and improvement is characterized by “a participatory Zeitgeist” [1], where participation is enacted within intellectual, social, political, cultural, and moral pursuits that are reflective of and shaped by a participatory spirit of the times, mood of the times, or spirit of the age [2]. There is no doubt that broader socio-cultural trends toward participation in health care intersect with this participatory Zeitgeist [3]. These trends include the involvement of the public in data collection for health research, initiatives in patient-led and crowdsourced research [4], the use of health care apps for self-management, greater emphasis on users in design phases, and embedding lived-experience within research and health care policy formulation. The participatory spirit also includes the drive for experience to be considered an equal source of evidence, as shown by the experts-by-experience and the engaged, empowered, and emancipated patient (e-patient) movements [5]. Alongside the e-patient movement is the enabled health care professional who is ideally supported by an elegant health care system designed to foster “unhurried and kind care” [6].

These shifts in participation are coupled with increased involvement in health systems planning, design, and quality improvement in unprecedented ways via participatory methods such as coproduction (including the variants of co-design, coinnovation, and cocreation) [7]. In this regard, participation has itself become a critical agent in health care planning, redesign, delivery, quality improvement, and systems transformation [8]. As the economist Elinor Ostrom noted, participation creates a synergistic value through the active roles people have in producing public goods and health care services that are of consequence to them [9]. While synergistic value is essential for recognition that people are coproducers of public goods, such as health care and associated services, participation in the "design and implementation of new policies, systems and services as well as patient care and clinical decision-making" [4] is now so prolific that it is time to genuinely consider the need for a science of participation in health care.

Why Do We Need a Science of Participation?

As a term, science refers to the systematic study, organization, and synthesis of knowledge of phenomenon and the mobilization of theories, concepts, and methods to better understand the what, why, and how that phenomenon works [10]. Calling for a science does not mean that existing theories and concepts are not available or relevant to building a systematic evidence base, or to synthesizing knowledge; indeed, there are long-standing traditions in the participatory paradigms [11]. Instead, the call for a science of participation suggests that there are currently three critical gaps that exist in the examination and interpretation of the phenomenon of participation. These gaps relate to:

- The need for a unifying language to bring together the many and varied ways that participation occurs in health care design, delivery, and improvement;
- The need to develop and apply explanatory theories and models to better understand how participation occurs and what is produced. This includes attending to different participatory roles of people, such as patients, the family/carers, clinicians/providers, designers, researchers, or government representatives, and;
- The need to generate a systematic evidence base of impact and outcome using theories, models, and measures developed by the participatory fields.

A science of participation will, by nature, be interdisciplinary, and it will intersect with paradigms across participatory design, participatory medicine, participatory research methods, and across approaches for engagement, collaborative decision-making, and change. A science of participation will mobilize existing knowledge, theories, and frameworks with a focus on unification, not replication, and synthesis, not reinvention. It will allow the identification of value creation in terms of impacts and outcomes from within the field. The following parts of this viewpoint will outline how a science of participation can contribute to addressing the three critical gaps of the phenomenon of participation.

Gap 1: The Need for a Unifying Language

A core rationale for a science of participation is that we are amid a scientific revolution in the participatory paradigm. Kuhn described the scientific revolution as a process by which normal science continues while there is a consensus about a framework, at least until anomalies emerge. Here we can use two examples to illustrate this point about anomalies. In the first case, coproduction and co-design frameworks in health care quality improvement have continued to be used as normative quality improvement methods. However, anomalies and facts that are difficult to explain in the context of the current paradigm have started to emerge and generate weaknesses. For example, cracks are emerging in the increased calls for evidence of impact and outcome from coproduction and co-design. Now, various authors suggest that it is the outcomes of coproduction and not the processes that achieve those outcomes that should be measured [12]. Coupled with this is a growing concern that the terms coproduction and co-design are losing meaning and creating weaknesses in the standard science too because they are being overused without attendance to the values, principles, and practices that ought to underpin them [13-15]. Indeed, there is variability in how coproduction and co-design are defined, so determining the different effects, impacts, and outcomes of various approaches is a challenge that will require an agreed upon vocabulary [14].

The second case for an emergent anomaly in the current science is illustrated in a recent article by DeBronkart on patient engagement [16]. In this paper, DeBronkart described how medicine has an outdated paradigm of the patient as a passive recipient, which has created weakness and the possibility for a new paradigm, that of the e-patient. This e-patient is a responsible driver of health, who shares part of the work as appropriate to their role and abilities [16]. Thus, in Kuhn's revolution, weaknesses in science provide the opportunity for a paradigm shift where underlying assumptions are re-examined, and a potentially new paradigm emerges [17]. This new paradigm in health care design, delivery, and improvement is a science of participation.

Gap 2: The Need to Develop Explanatory Theories and Models of Change

To date, participation in health care planning, design, delivery, and improvement has been primarily explained and examined through existing paradigms of implementation science, improvement science, and citizen science. While these are important sciences from which we can learn, they do not provide the field with the explanatory theories and models needed to re-examine the participation paradigm in conjunction with the anomalies and weaknesses outlined above, or concerning the phenomena of participation that is occurring in health care. That is, a science of participation is needed to identify the impacts and outcomes we ought to expect of coproduction and co-design. Moreover, it is needed to identify if participation (according to particular methods and approaches) in design, delivery, and improvement results in better patient experiences, quality care, and improved health outcomes. This includes understanding and evaluating the role of health care professionals in the participatory Zeitgeist.

To address these complexities, models and theories that have explanatory force for the phenomena of participation are required. In Table 1, the three currently existing and dominant paradigms used to describe participation in health care design, delivery, and improvement are briefly outlined [18-20]. Each of these paradigms has established traditions that are not entirely covered in their brief descriptions; however, the aim is to highlight the gaps in these sciences for attending specifically to participation. It is also acknowledged that there are several intersecting traditions across these sciences (eg, participatory design or distributed thinking and participatory medicine itself) that have influenced their development, which has not been covered in this summary.

In our re-examination of the assumptions that underpin participation in health care, there is an opportunity to synthesize what is a largely fragmented and inconclusive evidence base [19] and apply explanatory theories developed from our field. Existing work in participatory design can assist. Steen, for example, articulated the importance of virtue ethics in participatory design practice [21]. He outlined the essential virtues of cooperation, curiosity, creativity, empowerment, and reflexivity for designers and noted, drawing on MacIntyre's work in ethics, that virtues are not only about a disposition to "act…but also to feel in particular ways" [21]. More recently, an explanatory theoretical model of change identified eight mechanisms seen to be critical for facilitation of change in co-design and coproduction in health care improvement: recognition, dialogue, cooperation, accountability, mobilization, creativity, enactment, and attainment [2]. The explanatory theoretical model positioned these mechanisms within the relational contexts of co-design and coproduction activities and described some ideal transitions that might be expected in these activities. These included moving from being isolated (I), to somewhat recognizing experiences might be shared (I to Them), to sharing experiences and developing understanding (Them to You), to embracing a collective sense of change (You to Us), to all working together to achieve that change (Us to We) [2]. Such theoretical models are essential for building the conditions for participation and to interpret the impacts and outcomes.

Table 1. Distinction between citizen, implementation, and improvement sciences

	Citizen Science [15]	Implementation Science [16]	Improvement Science [17]
Historical tradition	Natural Sciences, such as bird observations, classifications, and collection of data by "non-scientists" for use by scientists. Participants as volunteer data collectors with aim to collect large datasets. Variants on this term are used in the literature and include civic science, community environmental policing, street science, popular epidemiology, and crowd science.	The implementation of evidence into practice and translation gap. Identification of evidence into practice roadblocks to improve implementation.	The quality chasm and improvement of quality of care to increase safety, with a focus on changing physician behavior. Highly influenced by the United States Institute of Medicine Quality Chasm reports.
Original purpose	To address some of the problems of time, space, and large amounts of data required for the biological sciences. People being able to collect data in different geographical locations. Some work was undertaken in medical research, such as Malaria Spot.	To promote uptake of evidence-based interventions into practice and policy. Early work had empirical focus with less attention to theory.	Systems-level work to improve the quality, safety, and value of health care. Premised on the idea that improvement would result in greater efficiencies in terms of both patient outcomes and cost.
Contemporary variants	A science that is focused on the needs and concerns of citizens and is developed and enacted by citizens. Shift from the person as the object of study to the citizen as a research subject (for data collection and analysis). Part of the evolution of digital humanities where large repositories of data can be collected (eg, Zooniverse platform). Also used in human-computer interaction studies to develop gamified solutions from data people contribute.	Progression of theoretical models and approaches to better understand and explain how and why implementation fails or succeeds. Identification of the conditions for implementation readiness in different settings.	Greater focus on the association between patient experience of care and quality, safety, and value of health care. Embedding public and patient in the processes of identification of systems of change areas, design, and co-development of solutions with professionals. Working in a partnership model between academia and frontline clinicians. Contribution to theories of how change happens.

Gap 3: A Systematically Generated Evidence Base of Impact and Outcomes

The call for a science of participation is coupled with the need for systematic examination and observation of impact and outcome. There has been a growth in literature outlining an expectation that we should see evidence of impact from coproduction [22-26], and there is an expectation that participation from patients, carers/families, and service users increases patient-centered outcomes, improves professional morale, and increases health and well-being; however, the measurement of this has been inconsistent and almost absent. To date, one cluster randomized controlled trial has been conducted to test the assumption that a participatory, co-design, quality improvement method may improve individual, psychosocial, recovery outcomes: the CORE Study (2013-2017) [23]. Some evidence indicates that collective coproduction reduces diagnostic error in hospitals [24], and survey results from the United Kingdom and from Australian and European nations have shown that a turn to participation via coproduction is more likely when government shortfalls in performance prevail [25].

When Don Berwick called for a science of improvement for health care over ten years ago, he highlighted that disputes for the development of a science were more likely to be about epistemological disagreement rather than the type of research required to generate an evidence base [27]. A distinguishing feature of the current participatory times is the increased recognition of the importance of lived-experience (experiential knowledge) and patient-led change [11]. This has traditionally raised an epistemological tension between advocates for participatory paradigms and evidence-based paradigms. It is time to cross the epistemological bridges and establish a science of participation that helps to explain impacts, document outcomes, and bring theories together into a unifying whole.

Almost 25 years ago, Ostrom also concluded that “contrived walls separating the analysis of potentially synergetic phenomena into separate parts misses the potential for synergy” [10]. The current state of play in participation in health care offers good ground for synergies among diverse theoretical and practical approaches from participatory design, participatory medicine, participatory action research, co-design and coproduction, to patient engagement, the e-patient movement, and enabled health care professionals. The next steps involve our building of a science of participation that contributes to the identification of the components and features of an elegant [6] health system to support participation. These steps include but are not limited to: (1) knowledge synthesis of the current phenomena of participation in health care design, delivery, and improvement to organize our somewhat disparate and divergent strands of fragmented evidence; (2) systematic study of participation to identify impacts and outcomes; and (3) harnessing existing theories, concepts, and methods to explain and interpret phenomena so that we might develop new models based on our science as appropriate. Now is the time for a science of participation.

Conflicts of Interest

None declared.

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Abbreviations

e-patient: engaged, empowered, and emancipated patient

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Viewpoint

Crafting Care That Fits: Workload and Capacity Assessments Complementing Decision Aids in Implementing Shared Decision Making

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Abstract

About 42% of adults have one or more chronic conditions and 23% have multiple chronic conditions. The coordination and integration of services for the management of patients living with multimorbidity is important for care to be efficient, safe, and less burdensome. Minimally disruptive medicine may optimize this coordination and integration. It is a patient-centered approach to care that focuses on achieving patient goals for life and health by seeking care strategies that fit a patient's context and are minimally disruptive and maximally supportive. The cumulative complexity model practically orients minimally disruptive medicine–based care. In this model, the patient workload-capacity imbalance is the central mechanism driving patient complexity. These elements should be accounted for when making decisions for patients with chronic conditions. Therefore, in addition to decision aids, which may guide shared decision making, we propose to discuss and clarify a potential workload-capacity imbalance.

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KEYWORDS

decision making; decision support techniques; patient-centered care

Minimally Disruptive Medicine

About 42% of adults have one or more chronic conditions and 23% have multiple chronic conditions (ie, multimorbidity) [1,2]. The coordination and integration of services for the management of patients living with multimorbidity is important for care to be efficient, safe, and less of a burden [2,3]; however, these services are often found to be suboptimal in clinical practice [4,5], which may lead to polypharmacy, increased treatment costs, side-effects, and unintended drug interactions [5]. In the end, this may overwhelm patients (eg, in what they have to do to control their disease) and in turn result in poor adherence, wasted resources, and poor outcomes [5-9].

Minimally disruptive medicine may optimize the coordination and integration of services [4]. It is a patient-centered approach to care focusing on achieving patient goals for life and health [5] by seeking care strategies that fit patient context [4]. The cumulative complexity model practically orients minimally disruptive medicine–based care [1]. In this model, the patient workload-capacity imbalance is the central mechanism driving patient complexity. Workload ("What patients have to do") encompasses the demands on patients' time and energy, including not only the demands of treatment and self-care, but also the demands of life in general. Capacity ("What patients can do") concerns patients' abilities and resources to handle health care and life work (eg, functional morbidity, financial/social resources, literacy). Workload-capacity imbalance can lead to problems accessing and using care, as well as enacting self-care [1]. Ultimately, this can result in poor adherence and poor patient outcomes [8-10].

All care strategies influence workload and capacity by affecting (positively or negatively) treatment and illness burden, respectively. For example, intensifying a patient's treatment may reduce his symptoms and illness burden at the cost of an increased treatment burden [1]. Awareness of a patient's capacity and workload is therefore critical in deciding on a patient's care strategy. Indeed, inattention to contextual information may lead to errors in this choice [11].

Shared Decision Making

When aiming for treatment decisions that result in desirable outcomes for the patient, active participation and engagement of both the clinician and patient is needed [12]. Shared decision making [13,14] is a patient-centered approach in which clinicians and patients work together to choose the best course of action for each patient's particular situation [15]. Although shared decision making often does not impact clinical outcomes [16-18], it tends to result in improved affective and cognitive outcomes [16] and can also help facilitate a stronger clinician-patient relationship and a shared understanding of treatment for patients' health and life goals [19,20]. Some ethical and clinical arguments also advocate for shared decision making [16,21-29], but despite this, it is not yet routine in clinical practice [30,31]. Multiple reasons are present for the suboptimal implementation of shared decision making, such as a perception-reality gap in which clinicians feel they are practicing shared decision making [31].

Shared decision making was first proposed in 1982 [32]. One of its first models was proposed by Charles et al [33,34], which later models built upon [33,34]. Since then, multiple definitions and models of shared decision making have been developed [35-39]. In this commentary, six key elements of quality shared decision making are defined [40,41].

- Situation diagnosis (understanding the patient's situation and establishing what aspects require action)
- Choice awareness (indicating that more than one option is available and that the patient's preferences are important in deciding on the course of action)
- Option clarification (describing the options available)
- Discussion of pros and cons (explaining the pros and cons of the available options)
- Deliberation of patient preferences (discussing the patient's preferences)
- Making the decision [40,41]

Some shared decision making models also include patient value elicitation as a key element [42,43]. We assume that value elicitation is implicitly handled in deliberation of patient preferences, as we expect that a patient's preferences also reflect the patient's important values. Furthermore, the order that elements are handled within the encounter is not fixed or important as long as all elements are included. In our opinion, the natural flow of the conversation is superior to the order of the key elements or the handling of value elicitation implicitly or explicitly. Namely, the clinician and patient should work together in partnership [4,15], instead of checking the elements' boxes in a mechanical way.

Shared Decision Making Decision Aids

Decision aids are designed to help patients participate in decisions that involve weighing the pros and cons of different treatment options and can help patients choose an option that is congruent with their values [44]. Decision aids are designed to supplement rather than replace clinician-patient interactions [42].

The International Patient Decision Aid Standards Collaboration developed a minimum set of standards for qualifying a tool as a decision aid, which states that all shared decision making key elements, except making the decision, should be incorporated in the tool to regard it as a decision aid [45]. Despite this, most decision aids developed for chronic illnesses are focused on communicating options and their pros and cons [41]. The situation diagnosis is less often included in decision aids for persons with chronic conditions [41], while understanding the patient's context is a prerequisite for care to fit the patient's context. Moreover, clinicians probe for contextual information less often than for biomedical information [11] and thus may neglect this information when making decisions with patients.

Workload and Capacity Assessments

To address the problem of neglecting contextual information, we propose to systematically supplement the use of decision aids for shared decision making with workload and capacity assessments [4]. Workload assessments aim at identifying the intrusiveness of health on life and to find opportunities for treatment plan augmentation. Capacity assessments aim at identifying contextual limitations in patients' capacity that may impact care effectiveness and that may be amenable to support or intervention [4].

The Instrument for Patient Capacity Assessment (ICAN) discussion aid is a tool that can be helpful in carrying out capacity and workload assessments [46,49]. ICAN is a paper-based tool that the patient can fill out while waiting for the clinician. It asks which areas of the patient's life (eg, family and friends, work, living situation) are sources of satisfaction, burden, or both. The patient is also asked whether things they have been asked to do to care for their health are a help, a burden, or both. Common self-management activities are listed (eg, taking medications and self-monitoring), and blank spaces are provided for any self-management tasks not listed. During the conversation the clinician is asked to review the three questions on the back of the aid: 1) "What are you doing to manage your stress?" (brings forth typical day-to-day and competing priorities), 2) "Where do you find the most joy in your life?" (to assess if the patient is struggling with biographical disruption from their treatment and illness), and 3) "What else is on your mind today?" (focuses on the visit today) [46,49]. Biographical disruption can be described as "an assault of chronic illness on often cherished conceptions of self, identity and life course, resulting in a fundamental rethinking of one's biography and self-concept in the light of the illness"

[47,48]. The clinician then explores what the patient reported on the form by asking “What stands out to you on this sheet you filled?” [46,49]. In this way, ICAN facilitates the situation diagnosis by elucidating and sharing insights about the patient’s current workload, capacity, and treatment burden to enact treatment plans [46,49]. A Web-based implementation tool kit covering workflow integration and conversation training is now freely available [49].

Discussion

Patients’ workloads and capacity need consideration when choosing care strategies. However, this is rarely done when performing shared decision making with patients. We thus propose to use workload and capacity assessments to add insight into the patient context more broadly than disease or decision specific decision aids.

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Conflicts of Interest

KB is the developer of the Instrument for Patient Capacity Assessment (ICAN) discussion aid. ICAN and its implementation tool kit are freely available for download and use at minimallydisruptivemedicine.org/ican. KB received a research grant from the Agency for Healthcare Research and Quality to develop the tool kit, but does not receive any compensation for downloads or use of the aid. KB is the course director of the Mayo Clinic Care that Fits conference where clinicians and researchers are taught in-depth methods for ICAN use in practice and participant course fees are paid directly to the Mayo Clinic. KB does not receive any additional compensation for the course.

The Mayo Clinic Knowledge and Evaluation Research Unit produces and tests shared decision making interventions for patients with chronic conditions. Tools are freely available at http://shareddecisions.mayoclinic.org and no income is generated from their distribution or use. This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors. TW’s travel grant was assigned based on a different project, which makes the current commentary a side-activity of TW’s Mayo Clinic visit. Therefore, the Amsterdam Public Health research institute was not involved in any activities related to the content of this work.

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Abbreviations

ICAN: Instrument for Patient Capacity Assessment

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Original Paper

Traumatic Brain Injury and Sexuality: User Experience Study of an Information Toolkit

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Abstract

Background: After having sustained a traumatic brain injury (TBI), individuals are at risk of functional impairments in information processing, abstract reasoning, executive functioning, attention, and memory. This affects different aspects of communicative functioning. Specific strategies can be adopted to improve the provision of health information to individuals with TBI, including the development of written materials and nonwritten media.

Objective: A user-centered design was adopted to codevelop four audiovisual presentations, a double-sided information sheet, and a checklist aimed at informing individuals about post-TBI sexuality. The last phase of the project was the assessment of the user experience of the information toolkit, based on the User Experience Honeycomb model.

Methods: Overall, two small group discussions and one individual semistructured interview were conducted with individuals with moderate to severe TBI.

Results: The participants mentioned that the toolkit was easily usable and would have fulfilled a need for information on post-TBI sexuality during or after rehabilitation. They mostly agreed that the minimalist visual content was well-organized, attractive, and relevant. The information was easily located, the tools were accessible in terms of reading and visibility, and the content was also considered credible.

Conclusions: Aspects such as usability, usefulness, desirability, accessibility, credibility, and findability of information were viewed positively by the participants. Further piloting of the toolkit is recommended to explore its effects on the awareness of the potential sexual repercussions of TBI in individuals and partners.

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KEYWORDS

user-centered design; user experience; traumatic brain injury; sexuality; health information

Introduction

Approximately 69 million individuals globally are victims of a traumatic brain injury (TBI) each year [1]. TBI is the leading worldwide source of morbidity and mortality caused by an injury, and its socio-economic impact is worth billions of dollars annually. After having sustained a TBI, individuals are at risk of functional impairments in information processing, abstract reasoning, executive functioning, attention, and memory, which affect different aspects of communicative functioning [2]. Individuals with severe TBI are especially likely to experience difficulties with understanding and assimilating new information

[3,4]. A variety of difficulties related to the ability to read, write, or communicate in general are also common. This means, for example, individuals can struggle with focusing on an individual line of text, or with understanding the content of written and verbal messages. These difficulties can involve low, trauma-related health literacy after hospital discharge, which implies that the individuals do not have the necessary capacity to seek, process, and understand the health information that would help them make informed decisions concerning the medical treatment they receive or their health situation [5,6]. In these cases, health care providers require the ability to shape the information to enhance communication and understanding [6]. To improve the provision of health information to individuals with TBI, the development of written, audio, and visual material is suggested [7,8], as well as the adoption of nonwritten media, like videos [9]. The variety of support solutions to be considered reflects the extent of the interindividual variability in post-TBI consequences that can be experienced.

Many impacts of TBI, including potential damage to the frontal and temporal lobe and its adverse effects on physical, cognitive, behavioral, and emotional functions, can result in sexual difficulties [10,11]. Among the most common repercussions are decreased desire, decreased ability to become excited and maintain excitement, and difficulty or inability to reach orgasm [11,12]. These effects are reported in both men [13-16] and women [15,17] and are more common among individuals with TBI than in the general population [18]. A decrease in the quality of an individual’s sexual life, an increase in their sexual dissatisfaction, and a decrease in their satisfaction with their relationships were also documented [19]. The decrease in the frequency of sexual intercourse [20] is higher in individuals suffering from depression as a result of TBI [21]. For this purpose, depression is considered the most sensitive negative predictor of post-TBI sexual dysfunction [20,22], along with older age of individuals [23]. Conversely, although it is less common, hypersexuality is sometimes observed [24].

However, regardless of its importance for many people with TBI, sexuality remains a rarely discussed topic during rehabilitation [13,25-29]. Studies highlight that most rehabilitation professionals usually take a reactive approach to addressing sexual dysfunction with their patients [30]. The issue is mainly discussed if the individual with TBI or the couple raises concerns. However, informing and educating single patients and couples about post-TBI sexuality is part of a holistic approach to rehabilitation [31]. The typical direct and indirect impacts of TBI on sexual functioning justify the need to inform patients, but very little information is available or had been adapted to this population’s needs. Accordingly, a French information toolkit on post-TBI sexuality was cocreated with individuals with moderate to severe TBI (MSTBI) and their life partners. It includes four audiovisual presentations, each intended for a particular group (single women, women in a relationship, single men, men in a relationship), a double-sided information sheet, and an 18-item checklist of common TBI repercussions on sexuality. The main objective was to develop supporting information material with consideration for post-TBI individuals’ impaired comprehension ability and specific design needs. This involves, for example, repeating the information and adding visual cues to support the retention of information [32]. A detailed description of the cocreation approach, including the choices of form and content for the different tools, is provided elsewhere [33]. Following this process, the user experience was assessed to uncover areas where improvements could be made to the tools. While there is no consensus on the definition of user experience [34], the adopted definition used in this study is the one by the International Organization for Standardization [35]:

> *A person's perceptions and responses that result from the use and/or anticipated use of a product, system or service.*

The objective of this paper is to report on the user experience assessment conducted with individuals with MSTBI. To date, the experience of individuals with MSTBI using information tools is poorly documented. This gap prevents researchers and clinical teams from adequately planning the design of educational materials that could provide accurate and understandable information best suited to this population’s specific needs.

Methods

Study Design

A user-centered design [36] was adopted for the larger study to encompass the cocreation process of the information resources [33]. This dynamic and iterative approach involves working with target users throughout the process of developing a product. For the user experience assessment, we carried out two small group discussions and one semistructured interview with individuals who had sustained an MSTBI. We used a semistructured interview guide to explore participants’ experiences of the information toolkit, and we based our interview guide’s questions on Morville’s User Experience Honeycomb model [37]. This simple model presents a honeycomb structure in which seven separate facets of the user experience are identified. It can be used to describe how individuals use, think, and feel about a product. To avoid misinterpretation and to increase the validity of participants with cognitive impairment answers, we designed clear and direct questions based on each subconcept (Textbox 1).

One of the seven facets of the user experience honeycomb model was not documented. The value of the product, which can be assessed by examining if the product advances the mission of the organization behind it, did not apply to our set of tools.

Textbox 1. Questions related to user experience and underlying concepts.

Findability

- Do you easily find the information you are looking for?
- Are the tools easy to navigate?

Accessibility

- Is the product designed so that even users with a disability can have the same user experience as others?
- Are reading and viewing tools accessible?

Usability

- Are these tools user-friendly and easily searchable?
- Are they simple and easy to use?

Usefulness

- Would these tools have filled a need during your rehabilitation?
- Are they useful?

Credibility

- Does the information transmitted in the tools seem credible to you?

Desirability

- Is the visual aspect of interest to you?
- Is it attractive?

Participants

A convenience sample of participants was recruited within a regional association of individuals with TBI, following receipt of ethics approval from the Research ethics board of the Centre intégré universitaire de santé et de services sociaux (CIUSSS) de la Capitale-Nationale. A case manager from the association made a preselection of participants based on the following inclusion criteria: have sustained an MSTBI (as documented in the association files), suffered the TBI no more than five years prior, have been discharged from a rehabilitation program, and are considered able, by the case manager, to take part of a discussion in the context of a small group for 45 minutes. An invitation was given to potential participants. Individuals willing to participate were contacted over the phone to confirm their interest and provide additional details.

Procedure

Small discussion groups were formed based on the participants' gender and relationship status. Participants were first invited to read the two-sided information sheet on common post-TBI repercussions on sexuality for as long as it took for them to either finish reading or to mention they could not perform the task. They also read the 18 elements of the checklist aimed at supporting individuals in identifying potential issues and raising their concerns with rehabilitation professionals. Then, individuals of the same gender and relationship status watched one of four 14-minute-long audiovisual presentations. Each of these four presentations addressed common issues related to sexuality that can occur after a TBI and was specifically aimed at a particular group (single women, women in a relationship, single men, and men in a relationship). The main subjects covered included the decrease or absence of sexual desire, erectile dysfunction, the decrease or absence of vaginal lubrication, pain, the difficulty or inability to reach orgasm, the inability to fantasize, and the decreased frequency of sexual intercourse. Other aspects that can impact sexuality, such as fatigue, depressive symptoms, lower self-esteem, and sensory deficit, were also discussed. The information sheet offered a summary, and the four narrated presentations provided more extensive information than the sheets. The learning objectives of the toolkit were to increase individuals with TBI's and their partners' knowledge of common repercussions of TBI on sexuality, to help them to identify potential solutions to common issues, and to normalize the discussion about sexuality during the rehabilitation process. The participants either watched the presentation as a group or alone. Two computers were at the participants' disposition. They had control over the computer, and they could playback the parts they did not understand.

Data on the user experience were collected using a purpose-designed interview guide. The first author led both the 45-minute-long small group discussions and the individual interview using a semistructured interview guide. Digital audio recordings were transcribed verbatim by a research assistant.

Data Analysis

Verbatim transcripts were analyzed using a deductive approach to thematic analysis [38]. The transcripts were first cross-checked with the digital audio recordings and observational notes of the group process. The transcripts were then anonymized and uploaded in Dedoose (SocioCultural Research Consultants, LLC, Los Angeles, California, United

States), an online mixed data analysis program. Two members of the research team (PMD and JD) independently read over the transcripts and coded the data according to the six predetermined themes, which included usability, usefulness, desirability, accessibility, credibility, and findability of information. After all the transcripts were coded, the few disagreements in coding were identified. Each was discussed, and a consensus was reached on the appropriate coding. Thus, a high level of intercoder agreement was attained [39]. Then, all quotes that had the same code were uploaded in an excel sheet presenting the participant's number (deidentified information) and the quote itself. The main ideas were identified and synthesized.

Results

Overview

Six adults with MSTBI participated in the user experience assessment (Table 1). An individual interview was carried out with one individual who could not be present at the time of the small group discussions.

Table 1. Description of the participants.

Participant	Sex	Age	Single	In a relationship
P01	F	42	✓	
P02	M	61		✓
P03	F	40		✓
P04	F	41		✓
P05	F	52		✓
P06	M	42	✓	

Usability

Usability refers to how well users can learn and use a product to achieve their goals. The participants positively evaluated this aspect, and they mentioned that the toolkit was easily usable. The availability of both the narrated presentations and the printed information supported their comprehension of the content. P04 mentioned that, because of problems related to the treatment and analysis of information, she could not have used the double-sided information sheet alone.

> *If you give me [this sheet], I will read it, but I won’t understand a thing.* [P04]

However, she said she understood everything from the narrated presentation, which included much more information. Participants shared their appreciation for the simple use of the web-based Prezi (Prezi Inc, Budapest, Hungary) software.

Usefulness

Usefulness requires that tools fulfill a direct information need of the target group. Results show that the usefulness of the toolkit was satisfactory. The participants reported that the tools would have met a need for information on post-TBI sexuality during or after rehabilitation. P03 shared that, had she watched the presentation during rehabilitation, she would have known she was not alone when dealing with a specific problem. P06 highlighted that the information presented normalized his personal experience and brought him relief. He had chosen not to ask questions to rehabilitation professionals, being too proud to raise concerns about his condition, but the tools brought him the answers he was looking for. He felt this was a fun way to raise awareness about both post-TBI sexuality problems and their potential solutions. Other participants, like P03, mentioned that partners would benefit from watching the presentation to acknowledge that the described issues are common:

> *it is important not to be the only ones saying, “I have a problem,” and for our partners to hear this from someone else.*

This was perceived positively since it could take the burden of sexual issues off the individuals' shoulders. Even participants who had received information on post-TBI sexuality during rehabilitation thought it provided complementary details. Others said that the toolkit would have supported a discussion with rehabilitation professionals. None of the topics were considered inappropriate or not useful.

Desirability

Desirability is the quality of a product that evokes emotion and appreciation by its image, identity, brand, or other design elements. The participants mostly agreed that the minimalistic visual content was well organized and attractive. P01 mentioned, though, that the basic aspect of the visual icons, as opposed to detailed pictures, could be modified to be more appealing. However, the same participant added that presenting more sophisticated visual content might distract the audience from the narrated content. She concluded it was preferable to keep it simple. P06 thought the visual aspect was well balanced, being neither too complicated nor too basic

> *It’s good, it was not childish, and was well presented. It was right on the target.*

Accessibility

Accessibility focuses on how an individual with a disability accesses or benefits from a product. It involves making the information readable and intelligible to the target audience, especially when the public is not a specialist in the field [40]. For individuals with MSTBI, considering their low level of health literacy, this might include the use of an appropriate language level, the availability of an alternative to written material, the presence of significant illustrations, and a consideration of the amount of information presented. The participants thought the information tools were accessible in terms of reading and visuals. The chosen font was easy to read, and the size was considered big enough. They thought the level of language adopted was appropriate and suitable for rehabilitation patients' consultations. The length of both the presentations and the written information was acceptable to participants. To this regard, P02 mentioned: "I didn't think it was too long."

Credibility

Credibility is the quality of being trustworthy and believable. This means that users need to feel that they can trust the information provided. For this study, the participants considered the information they were provided to be credible. A participant thought that the fact that the content was well explained supported his perception of credibility:

> *By the way you discuss [the issues], I would trust* [the information]

Findability of information

Findability is the ease with which information can be found, but it also involves the capacity to navigate through the toolkit and locate the required information. Well-organized information and the use of color and bold font to designate important words helped participants locate the content relevant to their situation. P06 said he quickly saw the information he was looking for:

> *When I looked at it earlier, I saw "decreased level of sexual desire" and "difficulty to reach orgasm." [This made me think] there it is, she is going to talk about what I wanted to talk about. I think it's great.*

Discussion

Primary Findings

The objective of this study was to assess the user experience of a toolkit on post-TBI sexuality in individuals with MSTBI. The evaluation focused on how well potential users could use the toolkit to meet their information needs on the subject, as well as how satisfied they were with the tools' design. Aspects such as usability, usefulness, desirability, accessibility, credibility, and findability of information were discussed and positively viewed by the participants. These results are encouraging for the dissemination to come. However, before reaching this stage, an evaluation of the acceptability of the tools will be carried out with rehabilitation professionals in the province of Quebec. Afterward, the tools will be made openly accessible through the Clinical practice guideline for the rehabilitation of adults with moderate to severe TBI's website [41].

To our knowledge, this is the first study to report on the user experience of individuals with MSTBI using post-TBI sexuality information resources. The limited availability of information resources addressing this specific subject might explain the difficulty in locating similar work despite extensive research. In the same vein, a recent scoping review on TBI education for adult patients and families has shown that the available literature on information delivery about TBI and its consequences mostly involves a population with mild TBI [42]. This reinforces our perception that studies similar to our work are still limited, despite the growing recognition of the necessity of an attitudinal shift that would lead to actively supporting both patient and public involvement [43].

The only other information resource on post-TBI sexuality to have been evaluated with documented results in the literature is the booklet entitled "You and Me: A Guide to Sex and Sexuality After Traumatic Brain Injury" [44]. While the user experience of this booklet was not explored, global satisfaction was assessed in a consumer evaluation [45]. A total of 12 individuals with brain injury were interviewed, and they gave a highly positive evaluation of the guide's practicality, length, informativeness, and the encouraging and comforting information provided. A subsample of eight individuals also had the cognitive ability to provide a dichotomous rating of each chapter of the booklet. These individuals thought all chapters were easy to understand and informative, but they provided a poorer rating of some chapters' relevance based on their situation or that of individuals in a similar situation (64.1%; 41/64).

Other studies with different populations with cognitive impairments also highlighted that the relevance of the information provided is enhanced by the participation of target users in the development process. Ruel et al conducted a research development project aimed at creating documentation on the services offered in a rehabilitation center for individuals with intellectual disabilities and autism spectrum disorder. Illustrated and plain language service descriptions, developed with and validated by the potential users, led to a better understanding of the services provided. These tools are relevant and useful to professionals for their interventions with users and their families [46]. The importance of using plain language and avoiding jargon was also supported by Sudore and Schinllinger in their study for patients with limited health literacy [47].

In the present study, the fact that the topics covered were based on information needs and expectations expressed by individuals with MSTBI led to a first positive evaluation of the toolkit usefulness. Moreover, the development of audiovisual presentations allowed for individuals with reading difficulty, and information treatment and analysis problems, to benefit from the information. It is hypothesized that these are more likely than conventional, author-driven leaflets and booklets to provide a positive user experience to the end-users.

Limitations and Future Directions

This study has several limitations. First, a selection bias cannot be ruled out. The selection criterion concerning the participants' ability to take part in a group discussion might have led to the recruitment of individuals who are not representative of the target population. In this regard, the functioning level of the participants may have been higher than that of most adults who sustained a moderate to severe TBI. The lack of representation of ethnic minorities and lesbian, gay, bisexual, transgender, queer (or sometimes questioning), and two-spirited (LGBTQ2+) communities is also worth noting. Our small homogeneous sample, therefore, limits the generalization of these results.

The analysis of qualitative content is, moreover, always open to interpretation, despite the precautions taken to adequately transcribe the interviews, to code their contents with rigor, and to correctly synthesize the main emerging ideas. The absence of prior assumptions and personal interests as to the orientations and aims of the project, however, mitigates the probability of causing confirmation bias.

An additional ongoing step before launching the tools online is the evaluation of the tools' acceptability by rehabilitation professionals. They will use the tools, when applicable, for six weeks. Participants will then complete an electronic assessment questionnaire consisting of closed-ended questions with Likert scales and open-ended questions, documenting the different subconstructs of acceptability [48,49]. Descriptive statistical analysis will be carried out, and a compilation of the answers to the open questions will be made. This will allow the identification of strengths and areas for improvement from a different point of view. The tools will be modified accordingly, and additional tools could then be created to fulfill specific needs.

Conclusion

This study reports on a user experience assessment conducted with individuals with MSTBI. Aspects such as usability, usefulness, desirability, accessibility, credibility, and findability of information in a post-TBI sexuality information toolkit were viewed positively by the participants. Further piloting of the toolkit is recommended to explore its effects on the awareness of potential sexual repercussions from TBI in individuals with MSTBI and on their partners. However, this study provides new information on the experience of individuals with MSTBI using information tools. It can be of use to researchers and clinical teams in planning the design of educational material, thus fostering the understanding of rehabilitation-related subjects in this population.

Conflicts of Interest

None declared.

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Abbreviations

CIUSSS: Centre intégré universitaire de santé et de services sociaux
LGBTQ2+: lesbian, gay, bisexual, transgender, queer (or sometimes questioning), and two-spirited
MSTBI: moderate to severe traumatic brain injury
TBI: traumatic brain injury

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Original Paper

Influence of Community and Culture in the Ethical Allocation of Scarce Medical Resources in a Pandemic Situation: Deliberative Democracy Study

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Abstract

Background: Stark gaps exist between projected health needs in a pandemic situation and the current capacity of health care and medical countermeasure systems. Existing pandemic ethics discussions have advocated to engage the public in scarcity dilemmas and attend the local contexts and cultural perspectives that shape responses to a global health threat. This public engagement study thus considers the role of community and culture in the ethical apportionment of scarce health resources, specifically ventilators, during an influenza pandemic. It builds upon a previous exploration of the values and preferences of Maryland residents regarding how a finite supply of mechanical ventilators ought to be allocated during a severe global outbreak of influenza. An important finding of this earlier research was that local history and place within the state engendered different ways of thinking about scarcity.

Objective: Given the intrastate variation in the themes expressed by Maryland participants, the project team sought to examine interstate differences by implementing the same protocol elsewhere to answer the following questions. Does variation in ethical frames of reference exist within different regions of the United States? What practical implications does evidence of sameness and difference possess for pandemic planners and policymakers at local and national levels?

Methods: Research using the same deliberative democracy process from the Maryland study was conducted in Central Texas in March 2018 among 30 diverse participants, half of whom identified as Hispanic or Latino. Deliberative democracy provides a moderated process through which community members can learn facts about a public policy matter from experts and explore their own and others' views.

Results: Participants proposed that by evenly distributing supplies of ventilators and applying clear eligibility criteria consistently, health authorities could enable fair allocation of scarce lifesaving equipment. The strong identification, attachment, and obligation of persons toward their nuclear and extended families emerged as a distinctive regional and ethnic core value that has practical implications for the substance, administration, and communication of allocation frameworks.

Conclusions: Maryland and Central Texas residents expressed a common, overriding concern about the fairness of allocation decisions. Central Texas deliberants, however, more readily expounded upon family as a central consideration. In Central Texas, family is a principal, culturally inflected lens through which life and death matters are often viewed. Conveners of other pandemic-related public engagement exercises in the United States have advocated the benefits of transparency and inclusivity in developing an ethical allocation framework; this study demonstrates cultural competence as a further advantage.

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KEYWORDS

pandemic; COVID19; influenza; disaster; preparedness; scarce resources; culture; ethics

Introduction

Legal and Ethical Preparedness for an Influenza Pandemic

Pandemic readiness and response activities are urgently underway, prompted by certainty about future global influenza outbreaks as well as the human and economic losses suffered during recent epidemics such as with the severe acute respiratory syndrome illness [1-3]. The pandemic of the novel coronavirus that first emerged in late 2019 has also acutely demonstrated the importance of robust preparedness and response systems. Legal and ethical matters have been a principal consideration for pandemic planning, domestically and internationally [4-10]. Of specific concern are public health measures that could adversely affect trade, travel, and economic stability; tip the balance between personal liberty and public wellbeing; or strain people's sense of justice or fairness [4,5]. Among the legal and ethical issues and dilemmas that the World Health Organization (WHO) first outlined for member states' consideration when undertaking pandemic preparedness planning are state of emergency declarations, movement restrictions, mass gathering prohibitions, school closures, isolation and quarantine, volunteer licensing and liability, drug and vaccine manufacturer liability, research participant protections, compulsory vaccination, and resource rationing [6].

Allocation of scarce lifesaving resources is as an especially fraught issue. Stark gaps exist between projected human health needs in a pandemic and the current capacity of public health, health care, and medical countermeasure systems. Finite production capacity and delayed vaccine development (ie, 4 months to produce the first doses of a novel pandemic strain vaccine and 6 months to generate a large supply) force the issue of who receives the initial doses [10,11]. What proportions of an antiviral stockpile to commit to treatment and prophylaxis, as well as who to prioritize constitute another dilemma [12]. Likewise, the projected number of US patients requiring an intensive care unit (ICU) bed and mechanical ventilation during a 1918-like pandemic eclipses current capacity by orders of magnitude [13]. In other contexts (eg, African countries with weak economies and endemic malaria and HIV/AIDS), a higher order predicament exists: whether to prioritize a response to a pandemic flu or to hyperendemic diseases [6,14].

Public Engagement With Pandemic Policies

Common to the current guidance on pandemic ethics—and specifically scarce resource allocation—is the call for public engagement (ie, the broader community's participation in the policy decisions affecting them) [4-9,15-17]. Pandemic ethicists invoke principles such as transparency, inclusivity, and education and information, citing multiple benefits. Authorities are enjoined to:

1. Open up decisions to scrutiny and articulate clearly the rationale behind specific choices. As a result, the public can be more confident that policies are not capricious, but reasonable, equitable, and in line with community views [4,5,7,9,16,17].
2. Elicit community input early on, especially that of disadvantaged groups. By doing so decision makers can more readily earn public trust, enhance social solidarity, add to a policy's legitimacy, and discern which approaches are socially acceptable and practically feasible [7-9,15-17].
3. Provide the public with accurate, timely, and understandable information about the pandemic threat, measures for personal protection, and collective actions for readiness and response. This can foster an educated populace—one better able to engage meaningfully with policymakers and play their own part in risk reduction [7,15,16].

Since these injunctions, public engagement in pandemic decision making has evolved beyond mere aspiration; although it has yet to become a widely used practice. Some arguments against it are that democratically elected representatives already represent population preferences, charged issues (eg, scarce resource allocation) could generate public emotion and confusion, and an inability to show how community views (particularly divergent ones) influenced policy could fuel public frustration [18]. Nonetheless, over the last 15 years, members of the public have had some degree of opportunity to inform potentially divisive pandemic policies in the United States [19-40] (see Multimedia Appendix 1 for more details) and elsewhere [41-47]. Often convened by public health agencies, and occasionally by university researchers, private citizens and interested stakeholders have participated in dialogue and deliberation sessions about pandemic dilemmas in which ethical principles (eg, liberty, beneficence, fairness) and technical matters (eg, disease containment, medical treatment) are inextricably bound.

Of the 18 known US pandemic-related public engagement exercises, more than half addressed how to ethically apportion finite lifesaving resources like vaccines, antivirals, intensive care, or personal protective equipment, while about a quarter debated burdensome social distancing measures (Multimedia Appendix 1). Of those discussions focused on scarce resources, nearly half considered prioritized access to intensive care (ie, ICU bed or ventilator). Other countries in which efforts have been made to glean diverse public views on ethically complex decisions during an influenza pandemic include Canada, Australia, New Zealand, and Switzerland [17,41-48]. Most of these studies addressed the allocation of scarce medical resources.

Cultural Aspects of Pandemic Ethics

An issue bearing upon influenza pandemic ethics in general, and public engagement in particular, has been what regard to give the diverse local contexts and cultural perspectives that shape the experiences of and responses to an otherwise global health threat [14,48]. The WHO ethical guidance for a pandemic highlights the need for international solidarity and shared principles, as well as a recognition that local circumstances and cultural values also influence ethical considerations [16]. In its pandemic ethical guidelines, the Centers for Disease Control and Prevention (CDC) proposes balancing centralized decision making at the federal level and implementation by state and local communities, and it advises consideration toward marginalized communities and groups whose cultural, religious, and other values require sensitivity [9]. Procedural ethics—in particular, bringing affected groups to the table so that their needs and views on a shared health threat are genuinely heard, and they see a policy as having been made fairly even if they may not agree with the final decision—are identified as a key means to respect cultural differences while advancing pandemic preparedness and response [14].

Culture and public engagement have surfaced as relevant issues for pandemic preparedness and planning, in particular among nations that include often marginalized indigenous populations. New Zealand's ethics guidance asserts that given the disproportionate impact of past pandemics, it is essential to mobilize expertise within Maori communities on how best to address their own situation and needs [17]. Similarly, calls have been made for greater inclusion of Aboriginal and Torres Strait Islander peoples in Australian national, state, and territory pandemic plans so that the heightened risk of these indigenous groups can be mitigated in more culturally appropriate ways [49-51]. Planning experiences with Canada's First Nations communities and American Indian and Alaska Native communities have also evidenced the value of participatory processes in uncovering the influence of local beliefs, values, and practices upon pandemic health and in strengthening the cultural competence, social acceptance, and practical feasibility of pandemic preparedness and response efforts that affect these groups [52,53].

Alongside in-nation differences, culture is also seen as a force shaping a nation's or entire region's pandemic approach. The notion of a "one-size-fits-all" plan for ethically allocating scarce medical resources butts up against divergent sociocultural conditions [14,16]. The higher status accorded to elders within many African societies—including those where the proportion of young children is higher than in other countries—may moderate the importance of the young as a priority group [14]. Among Asian countries where honoring older adults, senior personnel, royalty, and public service staff is a strong norm, and where family ties accord strong obligations, privileged access along social hierarchies and familial lines to nationally stockpiled antivirals is not necessarily seen as unethical [14]. Contrasts made with an American ethos of individualism and wariness toward government include Canada's communitarian political culture emphasizing peace, order, and good government [54,55]; Australia's broad embrace of a utilitarian liberal rationale prioritizing others' safety over individual autonomy [48]; and the United Kingdom's "Dunkirk spirit" engendering solidarity and public cooperation with state emergency efforts [56]. Noted attitudinal differences between the US and UK populations about pandemic preparedness may also reflect different health care traditions and the greater influence of religious beliefs in the United States [54,56].

Project Purpose

This US-based study considers the role of community and culture in the ethical apportionment of scarce health resources in a flu pandemic. It builds upon prior work by the authors exploring the values and preferences of Maryland residents regarding how a finite supply of mechanical ventilators ought to be allocated during a severe global outbreak of influenza [37-39]. Our initial aims were to develop, pilot, and apply a deliberative democratic procedure for conducting community forums state-wide that would inform a Maryland framework for the allocation of scarce health care resources in a disaster. An important finding was the need to convene a diverse, regionally varied sample of state residents to capture different ways of thinking about scarcity that local history and place seemed to influence [37,38]. Given the intrastate variation in the themes expressed by Maryland participants, the project team decided to examine interstate differences by implementing the same protocol elsewhere. We wondered if the same core values continue to hold in other areas of the United States, whether variation in ethical frames of reference exists at the US regional level, and what practical implications of sameness and difference may follow for pandemic planners and policymakers.

Methods

Study Location, Population, and Recruitment

This research took place in Central Texas. Community members were recruited from two areas: the greater San Antonio metropolitan area in Bexar County (comprising urban and semiurban communities with a high percentage of persons of Hispanic origin) and Colorado County (a rural county to the northeast of San Antonio with a largely white and less wealthy population). English and Spanish speakers over the age of 18 years were recruited in both of these areas through a variety of methods including: flyers posted in libraries, coffee shops, grocery stores, and other public locations; newspaper and radio ads; and social media postings. To ensure a diverse sample, members of underrepresented ethnic, racial, and socioeconomic communities were purposefully overrecruited.

Data collection occurred in-person and lasted approximately 7 hours. Data collection sessions were held on a single weekend day (Saturday in Colorado County and Sunday in San Antonio) in March 2018. Sessions were convened in hotel meeting rooms in centralized locations in each area to maximize accessibility. All participants were provided snacks and lunch and compensated US $100. Institutional review board committees at Johns Hopkins University and Texas State University approved the project methodology.

Deliberative Democracy Methods

Methodologically, this study used a deliberative democracy process that has been used with other potentially divisive policy decisions [57,58] and that the researchers had previously adapted to facilitate community discussions about the ethical allocation of scarce medical resources in a disaster [37,38]. Deliberative democracy is a qualitative method that provides a structured process through which community members can both learn facts about a public policy matter from experts and explore their own and others' views in a moderated community forum. As described in the literature, this approach provides opportunities for *knowledge exchange* between experts/policy makers and the public, *democratic accountability* through broad community representation in discussions that relates to the common good, and *innovation* when crowdsourcing generates new insights and solutions to existing problems [57,58].

In this project, the deliberative democracy process involved four distinct steps. First, community members were given details about a pandemic flu scenario and how scarce medical resources could potentially be distributed. This information was provided via an extended background document that participants read beforehand and an expert-led presentation at the start of the forum. Second, community members then met in groups of 4-7 where they engaged in a moderated discussion around the question: "What should we do in situations where there are more patients needing ventilators than there are ventilators to use?" During the discussion, participants were prompted to consider six ethical principles for prioritizing ventilator use: those most likely to survive the current illness; those most likely to live longest; those who have lived the fewest life stages; those with value to others in a pandemic; first come, first served; and a lottery. Third, at the discussion's end, each group developed 1-2 questions that they then asked to a panel of subject matter experts that included clinicians, ethicists, and disaster experts. Fourth, after this Q and A panel, and a break for lunch, moderated group discussions continued, this time focusing on the question: "Should healthcare providers be allowed to take a ventilator away from one patient who needs it to survive and give it to another patient who also needs it to survive?"

Data Collection and Analysis

Data were collected in two forms. Trained note takers documented each group discussion on laptops using a template developed for the project. These notes were supplemented by audio recordings made of all of the group discussions, which were later listened to by the note takers to expand their notes and check for accuracy.

Qualitative data resulting from the group discussions was later examined in an inductive manner via thematic analysis. After reading and rereading notes from the group discussions to ensure familiarity with the data, author EB developed a code list by examining the data relating to each ethical principle for prioritizing ventilator use (morning session) and participants' responses to the question "Should healthcare providers be allowed to take a ventilator away from one patient who needs it to survive and give it to another patient who also needs it to survive?" (afternoon session). This process resulted into an initial codebook that was re-evaluated and revised following subsequent iterations of coding, grouping codes into themes and re-evaluating the resulting coding schema. After two iterations of this process a final codebook of all codes and their corresponding themes was constructed. This final codebook was then used to re-evaluate every set of notes a final time. This process provided the opportunity to check that the coding, including the resulting themes, was an accurate representation of the group discussion data.

In addition to the group discussions, pre- and postsurveys were administered to all participants. The surveys collected information on participants' demographics and perceptions of the allocation of ventilators during a pandemic flu scenario, opinions on expert and community decision making, and opinions on the deliberative democracy process. For this study, the survey data was used to provide summaries of respondents' data so that direct comparisons could be made to the Maryland sample. These descriptive statistics were obtained through analysis in SPSS.

Results

Participant Demographics

A total of 30 community members participated in 6 discussion forums, 1 in Colorado County and 5 in San Antonio. One of the forums in San Antonio was comprised entirely of health professionals including clinicians, emergency preparedness experts, and public health officials. The separation of these individuals into a professional group was done to ensure that participants in other discussion groups were not influenced by perceived "expert" voices, and to collect data on the views and opinions of professionals whose work experiences afforded them additional insights into the topics discussed.

Participant characteristics are presented in Table 1. Participants ranged in age from 19-80 years, with the majority being 51-75 years of age. Men and women were represented in nearly equal numbers. Two-thirds of the participants identified their race as white, and nearly half of the entire sample noted being of Hispanic, Latino, or Spanish descent (a proportion smaller than the 60% of San Antonio residents and larger than the 30% of Colorado County residents who claimed Hispanic or Latino heritage in 2018). About a third of participants noted never having been married, and a similar proportion said that they had children living at home. Independents and Democrats were represented in roughly equal numbers, followed by Republicans. Religious affiliation was nearly entirely Christian or Catholic. Most participants had a college education or higher, and similar numbers earned US $40,000-$100,000 or over US $100,000.

Table 1. Characteristics of community forum participants convened in Central Texas, March 10-11, 2018.

Variable	Participants (n=30), n (%)
Age (years)	
≤25	3 (10)
26-50	9 (30)
51-75	16 (53)
≥76	1 (3)
Undisclosed	1 (3)
Sex	
Female	15 (50)
Male	14 (47)
Undisclosed	1 (3)
Ethnicity	
Of Hispanic, Latino, or Spanish descent	14 (47)
Not of Hispanic, Latino, or Spanish descent	15 (50)
Undisclosed	1 (3)
Race	
Black/African American	2 (7)
White	20 (67)
Asian	4 (13)
Native Hawaiian or other Pacific Islander	1 (3)
Other	2 (7)
Undisclosed	1 (3)
Marital status	
Never married	9 (30)
Married	16 (53)
Divorced/widowed	5 (17)
Children living at home	11 (36.6)
Political affiliation	
Independent	9 (30)
Democrat	10 (33)
Republican	6 (20)
None/other	5 (17)
Religious affiliation	
Christian/Catholic	28 (93)
Hindu	1 (3)
Other	1 (3)
College graduate or higher	21 (70)
Household income (US $)	
<40,000	5 (17)
40,000-100,000	12 (40)
>100,000	12 (40)
Undisclosed	1 (3)

It is important to note that the sample was small, consisting of only 6 discussion forums comprised of 30 total individuals. Such a sample size would be prohibitive in survey research; however, the sample size is appropriate to qualitative methods like deliberative democracy where findings are not considered to be generalizable in the traditional sense. The sample was also not representative of Central Texas as a whole; there was a bias toward an urban population and an overrepresentation of highly educated people. At the same time, diversity within the discussion groups in regard to age, education, race and ethnicity, and other factors likely mitigated some of these issues, as respondents within discussion groups spoke with and listened to one another. Regardless, it is important to keep in mind that the findings reported below are suggestive, not generalizable, of Central Texans' views regarding ventilator allocation and reallocation.

Broad Themes: Family and Fairness

Throughout the forum discussions in both Colorado County and San Antonio, two general themes emerged in relation to how community members felt that scarce medical resources should be allocated. The first was the importance of family. Respondents repeatedly referred to family—their own and others—in relation to decisions about ventilator use during an emergency. In some instances, this took the form of participants stating that they and others would be willing to sacrifice themselves for their family members, as one participant in Colorado County stated:

> *If you have a family that comes in, you have a mom, dad, and two kids, the parents are 9 times out of 10 going to tell you to go to the kids first. They're gonna say, 'We're all hurt, but go to my kids, then come back to me'.* [Participant CO-5]

In other instances, participants argued that familial roles should be an important consideration in making allocation decisions, as a respondent in San Antonio suggested:

> *We also have to look at their family situation. Are they a mother? I think that may play a little part of it.* [Participant SA 5-3]

More broadly, however, participants, and particularly the expert group in San Antonio, referred to the importance of the family as a key cultural value in central Texas that must be considered in light of any policy decisions. As one member of this group explained:

> *This [referring to the six ethical principles] is a medical model but people will be thinking in a very familial way. The medical standpoint is clear, but it will be implemented into a community who are extremely family oriented. They don't see themselves as 'one' they see themselves as a whole family.* [Participant SA 5-6]

The sentiment was echoed by another member of this group who stated:

> *In San Antonio, it's not what the patient wants it's what the family has to say. They make decisions together.* [Participant SA 5-3]

Without a familial focus, including involving families extensively in the decision-making processes, these experts, along with members of other forums in San Antonio and Colorado County, suggested that trust between clinicians and the broader community would be lost.

> *The decision-maker is bigger than the individual. Providers need to make a plan that will make everyone agree on what needs to be done. You need the cooperation of everyone by negotiating instead of telling the family by force because they are going to rebel.* [Participant SA 5-3]

As a solution, forum participants suggested that community discussions and education, well before an emergency happens, would enable families to discuss and accept policies beforehand.

The second broader theme emerging from forum discussions was the importance of fairness in deciding on a policy and implementing it. Participants in all discussion groups talked about this issue at length. Most participants stated that they had trust in clinicians generally; however, they were not all convinced that providers, or others in decision-making positions, would be infallible or completely unbiased, as one participant in San Antonio explained:

> *If a doctor is affiliated with a company, they will just do what the company tells them to do rather than do what he truly thinks would be appropriate, and that just does not seem fair to me. Unfortunately, many of us laypeople just don't have the knowledge needed to know how to react to such situations...* [Participant SA 4-2]

For allocations to be fair, participants argued that clear criteria need to be developed and followed consistently within and between locations.

> *Overall there is nothing fair about any of this [allocating scarce resources in an emergency]. So, the only way you can kind of say you're being fair is to be consistent.* [Participant SA 2-4]

In addition, multiple participants also suggested that how different populations might be placed at a disadvantage by a given criterion should be considered, as a participant from the expert San Antonio group explained:

> *What she was saying about where the hospitals are and the distributions of ventilators in hospitals... this easily provides disadvantages because of the distributions of hospitals in the cities. We are talking about social determinacy of health. It's a major disadvantage for greater populations living in the south and north. First come first serve may look good, but because of the disproportionate (distribution) of hospitals within the city I don't think it would work.* [Participant SA 5-7]

To facilitate fairness, forum members suggested several mechanisms that could be put in place before an emergency including a universal medical records system (as this would inform decisions based on who would be most likely to survive a current illness and live the longest) and the redistribution of ventilators so there is equal geographic coverage (both within cities and between counties in the state) based on current population sizes.

Specific Responses to the Six Ethical Principles

The themes of family and fairness were woven throughout the forum discussions; however, respondents also had specific thoughts on the six ethical principles, which, based on participants' survey responses (captured postevent), varied in terms of acceptable to not acceptable in the order of: survive current illness; live longer; value to others; fewer life stages; first come, first served; and lottery (Table 2).

Reasons given for favoring those most likely to survive the current illness and those who will live longer were similar. Respondents felt that in terms of saving the most lives, these two principles presented the best options.

> *I think from a numbers perspective this makes a lot of sense. You get the most survivors.* [Participant SA 2-3]

It was also noted that successfully treating people in a pandemic situation would possibly be a morale booster, as a participant in San Antonio noted:

> *If more people are recovering, then that could boost population morale and people could not freak out as much. Hearing good news in a tough time may make this a little bit easier for everyone.* [Participant SA 2-5]

In terms of concerns, respondents noted that it is impossible for clinicians to be certain of who will survive or live the longest, and that in regards to patients' health histories (a factor respondents felt would be important in determining who is most likely to live the longest) this criteria might cause patients or their family members to lie in order to "cheat the system".

Prioritizing those who have value to others in the pandemic—including clinicians and vaccine developers—received mixed responses; although this principle was ranked third based on survey data. In favor of this principle, participants noted the importance of health care workers, especially clinicians with specific specialty training and in medically underserved locations. At the same time, several forum members noted that this principle has great potential for bias (ie, health care providers favoring their colleagues) and that this principle has the potential to open the door for prioritizing others based on things like socioeconomic status.

> *[I]f we say we are prioritizing health care providers or people who could help, I'm sure that someone could make a case for someone who just happens to make more money than everyone else. They may be more financially able to help the recovery... and squeeze into being considered.* [participant SA 2-5]

In relation to prioritizing those who have lived the fewest life stages, forum participants repeatedly noted that putting children first was an important cultural value and critical because children represent the future, as a Colorado County resident stated:

> *You just generally want to help the children, or the younger people, so they can be prosperous and survive. It's harder to see a baby die, or a young kid. You want to help them as best you can versus someone who has already lived and had experience in life.* [Participant CO-5]

At the same time, respondents also noted that the differentiation of life stages beyond infancy and childhood are less clear, that the principle does not resolve situations in which the patients being considered are the same age, and that this principle is biased against older adults who have experience and knowledge that should be respected and preserved.

The most unpopular principles in the survey and in the discussions were first come, first served and a lottery. Participants generally agreed that both of these approaches could be objectively fair; however, they also noted that they were the least likely to save lives:

> *It does not save the most number of lives....But when in a critical situation, one might need to make more choices than just picking a number out of a box.* [Participant SA 4-5]

Additionally, forum members in both Colorado County and San Antonio noted bias in favor of those who live in urban areas close to hospitals (a factor impinging upon first come, first served) and the social unacceptability of a lottery because it is seen as a form of gambling.

> *On a moral and religious aspect we'd be leaving everything to luck. Like, are you going to leave life to luck? Are we going to play bingo with my life?* [Participant SA 1-6]

Table 2. Proportion of responses for how often each principle should be used in making allocation decisions across all respondents, with Texas/Maryland comparison.

Principle	Never or rarely		Often or always	
	Texas (n=30), n (%)	Maryland (n=310), n (%)	Texas (n=30), n (%)	Maryland (n=310), n (%)
Survive current illness	2 (6.7)	25 (8.1)	26 (86.7)	220 (71.0)
Survive longest	8 (26.7)	50 (16.1)	15 (50.0)	174 (56.1)
Fewest life stages	9 (30.0)	87 (28.1)	10 (33.3)	93 (30.0)
Value to others	6 (20.0)	65 (21.0)	12 (40.0)	149 (48.1)
First come, first served	12 (40.0)	149 (48.1)	8 (26.7)	65 (21.0)
Lottery	24 (80.0)	254 (81.9)	3 (10.0)	12 (3.9)

Reactions to Withdrawing a Ventilator to Give to Someone Else

Participants were reluctant at first to say if it was ever acceptable to remove a ventilator from someone who needs it to survive and give it to someone else who also needs it to survive. Some wanted to avoid judgment on such a complex issue; others felt unqualified to make the call. As people struggled to come to terms with the scenario, some ideas proved more supportable than others. Saving lives was a commonly expressed objective. Participants generally agreed that it was acceptable to remove someone from a ventilator if the patient's health was not significantly improving and if the equipment might ultimately preserve another life: "If a person's...getting worse and worse...and they're obviously not going to survive, it makes sense to me to remove the ventilator and give it to someone else who could do better" (Participant SA 4-3). Respondents felt that having an established timeframe would limit the arbitrary reallocation of the ventilators; although they expressed divergent views about the proper timeline.

Some individuals, however, objected to the reallocation of ventilators entirely.

> *Life is important to everyone. If someone is on a ventilator that means they have a need....I don't see a reason to ever take it away.* [Participant SA 5-2]

Fairness emerged as one reason for their objections, as in it would be unfair to remove a ventilator from someone who had already met the criteria to receive one in the first place. When comparing allocation and reallocation scenarios, some individuals expressed the feeling that choosing to give one person a ventilator over another person was different from removing a ventilator from a patient when death would certainly follow. For some participants, playing a role in someone's death was an action set aside for a high power.

> *It doesn't sound as natural. I guess 'cause you're already hooked up.... Morally I think of God's plan to how things should work out. It just... it's different.* [Participant CO-2]

Doctors frequently were identified as trusted arbiters in the difficult decision to remove a ventilator.

> *...[T]he doctor has the last word. In a situation in which you have two car crashes, he's not going to flip a coin to see who is going to get helped. He makes the decision based on his academic background and the values in the community.* [Participant SA 4-2]

During deliberations, however, a tension often arose between participants wanting to rely on medical professionals and being worried that mistakes would still be made. Giving doctors access to "more data" and "predictive modeling", in addition to their own expert opinions, was offered as one way to reduce such mistakes. To foster community faith in health professionals' reallocation decisions, participants proposed greater transparency: advising the public in advance of a crisis what criteria will be used, involving the patient's family in the decision making, and alerting patients at the outset about the possibility of ventilator removal: "If I know the criteria going in and out, I think that is fair" (Participant SA 2-3).

A majority of participants did agree that there are situations in which health care providers should remove a ventilator from one patient who needs it to survive and give it to another who also needs it to survive. Nonetheless, a significant portion still remained against or ambivalent about this scenario (Table 3).

Table 3. Proportion of responses to the question, "Are there situations in which health-care providers should remove a ventilator from one patient who needs it to survive and give it to another who also needs it to survive?" with Texas/Maryland comparison.

Responses	Texas (n=29), n (%)	Maryland (n=310), n (%)
Yes	18 (62.1)	195 (62.9)
No	4 (13.8)	68 (21.9)
Unsure	7 (24.1)	47 (15.2)

Discussion

Principal Findings

In anticipation of extreme health emergencies like a pandemic influenza or COVID-19, authorities at all levels have been developing ethically informed frameworks for the allocation of scarce medical resources. This study's purpose was to investigate whether core values concerning scare resource allocation exist in different regions of the United States, while considering the practical implications of sameness and difference for emergency preparedness and response policies.

Comparison of US Public Engagement Findings

Despite distinct geographies and histories, Maryland and Central Texas residents expressed a common, overriding concern about the fairness of allocation decisions and their implementation: What if someone tries to "game the system" (eg, give false medical histories to circumvent a survivability assessment)? What if a clinician makes an error in judgment about who really needs a ventilator? What if a first come, first serve scenario means that people who live in "hospital-poor" city neighborhoods and rural towns miss out on lifesaving equipment? [37]. The two groups similarly advised on how to build up public faith that the burdens of disease and benefits of treatment are equitably distributed: conduct public education in advance, make the criteria for allocation decisions transparent, and coordinate facilities across the state so that the allocation criteria are consistently applied [37].

Uniting on another point, the two states' participants identified "survive current illness" and "live longer" as the most acceptable ethical principles that should be used "often" or "always" in making allocation decisions (Table 2), with even more Texans embracing survivability. Both groups also expressed a similar degree of moral ambivalence toward the act of withdrawing a ventilator from someone who needs it to give to another person who also needs it (Table 3). Actively revoking life-sustaining support from a dependent patient, even if to help someone more likely to benefit, was, for many Marylanders and Texans, not morally equivalent to withholding the resource in the first place—whether grounded in spiritual matters (eg, only a higher power has the right to determine a person's time) or a sense of fair play (eg, taking a ventilator away to be allotted to someone was unjustly changing the rules of the game).

The Central Texas findings also resonated with sensibilities expressed in public engagement exercises convened elsewhere on the allocation of scarce medical resources in a pandemic. Withdrawing lifesaving care similarly evoked concern in Seattle and King County, WA [30,31]. Fairness as a rationing principle also prompted the most discussion in Minnesota-held forums [24,26]. Harris County, TX residents equally embraced having an advance allocation plan that could inform doctors' allocation decisions during a crisis [34]. Along with Central Texas residents, communities from the Gulf Coast, the mid-Atlantic, the Northwest, and the Midwest converged upon the idea of first helping those most likely to survive, thus saving the most lives [28-31,34,37-39]. That certain foundational principles cut across the country's distinct regions augurs well, in that a set of core values could potentially sustain a productive national conversation and potential policy framework on an ethically complex matter.

Family-Centered Approaches to an Allocation Framework

The Maryland and Central Texas forums evidenced common views and values, but dissimilarities also emerged. Participants from both states spoke to a willingness to make sacrifices for their kin, namely, a parent's or grandparent's desire to give their allotted ventilator to children in their family. Nonetheless, Central Texas deliberants more readily expounded upon *family* as central to the question of how best to allocate scarce medical resources. Survivability was an important clinical consideration, but so too was the social consideration of a patient's familial role (eg, are they a mother). Moreover, San Antonio participants, particularly the expert group, singled out family as a key local cultural value. Authorities, they argued, who want to connect effectively with local residents and gain their trust in regard to allocation decisions, should approach families, not individuals, as the partner to engage in understanding prioritization rationale, especially in the case of a withdrawal scenario.

The emergence of family during the Central Texas deliberations as a principal lens through which to view life and death matters has a strong regional cultural basis. Social and behavioral researchers have theorized *familismo*, family-centeredness, as a core cultural ideal among Mexican-origin peoples in particular and, to an extent, Hispanics more generally [59]. Features of the *familismo* value system include obligations among family members (nuclear and extended) to provide economic and emotional support, perceptions of kin as a reliable source of help, family as a core aspect of self-identity, and consultation and conformity with family regarding personal decisions and actions [60]. Mexican Americans tend to view life-threatening illness as a problem for the entire family and health care decisions as a collective matter, in contrast to the privileging of autonomy in Anglo-American medical ethics [61]. These sentiments were particularly present among the groups convened in San Antonio, a city in which a majority of residents claim Mexican heritage; however, family was also a recurrent theme among the study's predominantly white participants from rural Colorado County. This is likely indicative of a cultural bias within the region where the family is a central institution [62,63].

Producing and Practicing a Culturally Competent Allocation Policy

Ethicists working on pandemic influenza preparedness have outlined the benefits that public engagement principles of transparency, inclusivity, and education and information afford. When authorities subject their decisions and rationale to public scrutiny, communities can see that policy choices are neither arbitrary nor dismissive of local sensibilities [4,5,7,9,16,17]. Seeking the public's counsel—including that of marginalized, underrepresented groups—on potential policy directions can foster greater trust in authorities, strengthen legitimacy of decisions, and enable successful implementation [7-9,15-17]. Informing the public in advance about pandemic risk as well as individual and collective ways to manage it can generate a populace who is better equipped to exercise responsibility for community well-being [7,15,16].

A majority of public engagement exercises convened in the United States around pandemic influenza, including those held in Maryland and Texas by the study team, have worked to embody the principles of transparency and inclusivity. They have done so primarily by involving participants who represent the jurisdiction's larger, heterogeneous population (Multimedia Appendix 1). This sampling approach lends greater credibility to claims of a democratic process, that is, genuinely including the people's voice in policy discussions. Moreover, most pandemic-related public engagement initiatives have endeavored to discern prevailing community values for policy makers to consider. From Maryland to Texas, areas of agreement abound both on an allocation framework's substance (eg, "survive current illness" and "live longer" as the most acceptable principles) and its implementation (eg, keep planning transparent, apply framework consistently) [37-39].

At the same time, public deliberation forums have also revealed instances of divergent thinking; although this has been a lesser analytic focus for most other conveners (Multimedia Appendix 1). Holding 15 public engagement forums across Maryland, the study team heard residents speak about fairness in concrete, local, place-based terms, not in the abstract [37,38]. Residents of historically underserved Baltimore city neighborhoods worried about being passed over again; citizens of outlying, rural districts feared that city dwellers would get a disproportionate share of ventilators, just like state revenues. Cognizant of these concerns, state and local health authorities can communicate before, during, and after an emergency about ventilator allocation with greater empathy and in terms that are salient for specific communities.

Contrasting the Maryland and Central Texas forums demonstrates another kind of difference: US regional and ethnic cultures that can affect the development, implementation, and communication of an ethical allocation framework. Foreseeing such an issue, the CDC's pandemic ethical guidelines advise striking the right balance between centralized decision making at the federal level and implementation at state and community levels where local situations and sensitivities can be better assessed and addressed [9]. *Familismo* has greater relevance in the southwestern United States than in northern, midwestern states where few Hispanics reside. In a state with many Mexican heritage residents and a wider regional and cultural emphasis on family, Texas health authorities may find themselves having to weigh family as a prioritization principle more heavily than peers in other US regions. Another public engagement exercise that oversampled for Spanish speakers found, for instance, that Hispanics prioritized children and pregnant women at much higher rates than non-Hispanics [31]. In addition, the varying religious compositions of US regions may shape the ethical principles that matter most to local communities in relation to allocation matters. Christianity, for instance, represents 59% of the religious composition of adults in New York City, in contrast to 77% in Texas [64].

Familismo also has implications for framework implementation and communication. If a state like Texas develops a framework to standardize allocation decisions, then community-level health authorities and clinicians could localize how it is procedurally administered and conveyed to the wider community. This could help create a more culturally competent approach to scarce resource allocation. In respecting *familismo*, for instance, health facilities could adopt communication strategies that strengthen cross-cultural competency among critical care staff [65]. Moreover, health facilities could establish a process that gives family members a chance to confer among themselves when the patient no longer benefits from mechanical ventilation and withdrawal is called for. The emphasis within the *familismo* value system upon the collective and duty to the whole also provides a salient moral frame through which local authorities could communicate effectively about the need for developing and applying an allocation framework, and the importance of taking proactive measures that would help delay the implementation of an allocation framework in the first place, such as strengthening medical surge capacity.

Limitations

Claims regarding Central Texas regional culture are limited by a small sample size and a bias toward an urban population with a high percentage of persons of Mexican origin. In this segment of Texas, cultural geographers recognize a convergence of four distinct cultural identities: the Anglos of Southern tradition, the Catholics of strong European heritage, the Hispanos, and the African Americans [62]. Due to financial constraints we were not able to employ random sampling. That small groups of participants may not capture broader community interests and views is a frequent critique of deliberative methods [66]. The sample may not represent the region's four cultural streams, but intragroup diversity (Table 1) and the Maryland contrast nonetheless facilitated a limited investigation of sameness and difference. The time required to attend the deliberative sessions (7 hours) may also have introduced nonparticipation bias.

Conclusions

Ethicists working on pandemic influenza have proposed that procedural ethics—namely, bringing together diverse communities to weigh in on a policy decision that may affect them so that authorities fairly consider their views and needs—are an important means to respect cultural differences while advancing the common good of stronger preparedness and response systems [14]. Conveners of pandemic-related public engagement exercises in the United States have similarly advocated the benefits of transparency and inclusivity in the development of an ethical framework to guide the allocation of finite medical resources such as mechanical ventilators during a public health catastrophe (Multimedia Appendix 1). The Maryland and Central Texas comparison that reveals *familismo* as a distinctive regional and ethnic core value, moreover, demonstrates that public engagement efforts can ultimately enhance the cultural competence of an ethical allocation framework's development, implementation, and communication [52,53].

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Authors' Contributions

All authors of this study were involved in the conceptualization of the project, the collection of study data, and the writing of this report.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Public Engagement Initiatives for Influenza Pandemic Preparedness, 2005-2017.
[DOCX File , 24 KB - jopm_v12i1e18272_app1.docx]

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Abbreviations

CDC: Centers for Disease Control and Prevention
ICU: intensive care unit
WHO: World Health Organization.

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Original Paper

The Challenges of Including Patients With Aphasia in Qualitative Research for Health Service Redesign: Qualitative Interview Study

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Abstract

Background: Aphasia is an impairment of language, affecting the production or comprehension of speech and the ability to read or write. Aphasia is a frequent complication of stroke and is a major disability for patients and their families. The provision of services for stroke patients differs across health care providers and regions, and strategies directed at improving these services have benefited from the involvement of patients. However, patients with aphasia are often excluded from these co-design activities due to a diminished capacity to communicate verbally and a lack of health researcher experience in working with patients with aphasia.

Objective: The primary aim of this paper is to identify approaches appropriate for working with patients with aphasia in an interview situation and, more generally, determine the importance of including people with aphasia in health service improvement research. The secondary aim is to describe the experiences of researchers involved in interviewing patients with aphasia.

Methods: A total of 5 poststroke patients with aphasia participated in face-to-face interviews in their homes to gain insight into their in-hospital experience following their stroke. Interviews were audio-recorded, and thematic analysis was performed. The experiences of the researchers interviewing these patients were informally recorded postinterview, and themes were derived from these reflections.

Results: The interview technique utilized in this study was unsuitable to gain rich, qualitative data from patients with aphasia. The experience of researchers performing these interviews suggests that preparation, emotion, and understanding were three of the main factors influencing their ability to gather useful experiential information from patients with aphasia. Patients with aphasia are valuable contributors to qualitative health services research, and researchers need to be flexible and adaptable in their methods of engagement.

Conclusions: Including patients with aphasia in health service redesign research requires the use of nontraditional interview techniques. Researchers intending to engage patients with aphasia must devise appropriate strategies and methods to maximize the contributions and valuable communications of these participants.

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KEYWORDS

stroke; communication; research; qualitative; aphasia; participatory research

Introduction

What is Known?

Patient involvement in health care service redesign is recognized as an important component of ensuring quality, evidence-based care. Termed co-led redesign, this method has been frequently utilized to develop and deliver improved health care services for a variety of patient groups. For instance, successful outcomes from co-design have been shown in chronic illnesses [1] where patients were involved in developing technological solutions for mobilizing personal strengths, in the provision of youth mental health services [2], and in developing stroke rehabilitation priorities [3].

Stroke is the leading cause of aphasia [4], a disorder of communication, and Australian data suggests that approximately 29% of patients with acute stroke present to hospital with aphasia [5]. About 40% of all people who experience a stroke develop aphasia, with variation in the severity ranging from mild cases, with occasional difficulties in word-finding, to total loss of oral output [6]. It is one of the most devastating symptoms in stroke survivors and severely affects patients' communication, quality of life, and social interactions [6].

What is the Gap?

Although a number of methods have previously been described for involving patients with aphasia in qualitative research [7-10], there is little information in the literature describing why it is important to include patients with aphasia in co-design research or the experiences of the research team members who are involved in obtaining meaningful data from patients with aphasia. The primary aim of qualitative research is to understand the experience from the perspective of the participant. However, the researchers, either consciously or unconsciously, bring to the research setting their predispositions, assumptions, and beliefs, which may or may not be beneficial [11]. In this case, face-to-face interviews require careful thought and consideration of the type of aphasia the patient has, how best to communicate with the patient, and how the patient is most easily able to communicate with the interviewer, which is something that an inexperienced interviewer may find confronting and challenging.

What is the Purpose?

This study aims to highlight the need for the use of appropriate methods to interview people with aphasia as part of a co-design approach to health service improvement, based on the experiences of researchers who interviewed stroke patients with aphasia. This paper also discusses what was learned from the experiential accounts of patients with post-stroke aphasia regarding health service improvement. This study fills a gap in current knowledge around the importance of including individuals with aphasia in broad qualitative research that is not specifically targeting people with communication difficulties, and how the experiences of researchers may affect the outcomes of this research.

Methods

Recruitment

Overall, 117 poststroke patients from a rural health district were invited to participate in face-to-face interviews as part of a local, co-design, health service improvement initiative. A total of 27 (23%) patients accepted this invitation. Of these patients, 5 (19%) had some form of communication difficulty (aphasia), which was not known to the researchers in four cases before conducting the interviews.

Procedure

The interviews were held in a place of the patient's choosing. In total, 22 interviews were held in the patient's home, 3 over the phone (interstate residents), and the remaining 2 in a public café. All interviews with patients with aphasia took place in the home of the patient, with their spouses, family members, or carers present as required or requested. Each interview consisted of a set of semistructured questions, with time allowing for the conversation to flow in the direction set by the participant and their family or carers. Interviews with participants with aphasia ranged in time from 47 minutes to 1 hour and 50 minutes, which was consistent with interviews with participants without aphasia.

Analysis

All interviews were audio-recorded, and this data was later transcribed for thematic analysis, which will not be presented in this paper. The researchers who were involved in interviewing the participants with aphasia reflected on their experiences through conversations with the research team, and reflections were documented and reviewed. This paper will present the reflections of the researchers as major themes from the data.

Results

Researcher Technique and Experience

The results suggest that there were three major factors/themes that influenced researcher experience when interviewing patients with aphasia: preparation, emotion, and understanding.

Preparation

Having not known, or inquired, in advance about any potential communication difficulties for the poststroke patients, the researchers conducting interviews with individuals with aphasia felt unprepared in several ways. Firstly, they felt that they were ineffective at communicating with the participant and their families/carers:

> *I felt as though I was never looking at the right person or asking the right questions.* [Researcher 1]

Secondly, the ability to record the nonverbal communication was hindered as the research plan only included an audio recording of the interview. In this instance, researchers made written notes after the interview based on what was recalled about the nonverbal communication.

> *I found myself sitting on a public park bench scribbling as much as I could remember about the*

> *way he had interacted with me non-verbally.* [Researcher 2]

Emotion

When it became apparent that the participant had aphasia, this elicited a range of emotions within the researchers. These included relief that there was a family member (or carer) present, anxiety about being able to effectively communicate, embarrassment at not being well-prepared, and fear of being judged.

> *I was shocked to see that the patient was having difficulty speaking but was very relieved when his partner was able to fill in the gaps for me.* [Researcher 3]

Understanding

It was important for the research team to ensure that the information they collected during the interviews was a correct reflection of what the participant wanted to share. At times, it was physically difficult to understand the conversation and its context. It was also difficult for the researcher to develop an understanding of the patient experience due to the challenges faced because of the communication deficits.

> *I could interpret some of what he was saying but it was hard for me to gain an understanding of where it fit in his care or his experience.* [Researcher 1]

Patient Experience

The interview data collected from the five patients with aphasia indicated a perspective of poststroke care which differed from those who did not have communication deficits. Themes highlighted more often by participants with aphasia were the need for a more focused approach to poststroke communication development, family involvement, and ongoing education. The full results and thematic analysis will be published at a later date.

It was noted that during transcription there were gaps in the interpretation of the material collected during the interviews with patients with aphasia. These gaps could have been avoided through the use of different methods of recording, either by recording video as well or by having a second interviewer involved in note-taking. It was noted that there was a disconnect between the experience within the interview and the recording that was translated. After spending some time with the participants a clear method of communicating was often established, though it was not always verbal. For example, confirming with a participant what it is that they were saying often resulted in nodding, clapping of hands, or using another form of movement to respond. This exchange was lost in the recording and the translation and was difficult to understand without having been personally involved in the interview. Other methods of communication included patting the interviewer's hand or leg when wanting to speak, showing excited facial expressions when confirming a story or comment, and squeezing the hand or the leg of the interviewer when having something to say.

Discussion

Primary Findings

This study aimed to provide an improved understanding of working with patients with aphasia in a qualitative research context. We have described the approach used in our study to interview poststroke patients with communication difficulties to highlight the weaknesses of not having a good prior understanding of working with this patient group. Audio recording as a blanket means of data collection is inadequate for interviewing patients with aphasia, and utilizing methods such as video recording [7,8] or amending the question material [9] would have been beneficial in strengthening this research.

Before the interviews took place, participants with aphasia did not necessarily disclose their communication difficulties or the extent to which they relied on nonverbal communication. This created a range of complexities for the research team, most notably that they were underprepared. At times, the interviewers questioned their techniques, as they found themselves assisting participants by finishing sentences, offering words to complete stories, or prompting the patient about what they were meaning to say. Again, despite having much experience with face-to-face interviews, working with participants with communication difficulties can be challenging and confronting at times, creating a sense of anxiety, frustration, and embarrassment. Having family members present in some of the interviews helped not only in terms of communication, but also to jog the memory of the patient about their experience in the hospital. It was noted that participants who had difficulty communicating verbally often relied on their family members to speak for them, consistent with previous findings [10]. This approach assisted the researcher in gathering experiential information, but the context of some conversations remained unclear.

It was also noted that there seemed to be no frustration among the participants, their spouses, or family members during the interviews, which was a surprising and pleasing finding given previous research about the difficulties faced by patients with aphasia and their families [12]. This process and the perceptions of family members confirm that patients with communication difficulties were grateful to have their experiences heard, and they were happy to provide their opinions and feedback on the health care services they received.

Interviewing participants as part of qualitative research has been nominated as a gold standard method over many years, with audio recording considered a sound choice. However, working with participants who have communication deficits shows that verbal interviews often lack content, including emotion, which can be an important factor in discussing experiences. In addition to the barrier present in communicating with the participant with aphasia, there is difficulty in judging thir response, particularly if a voice recorder is the only method utilized. Based on our results, in a co-design study, it would be beneficial to consult with the patient or their family/carer before the interview to ascertain what methods they are most comfortable with and how they see themselves being best able to contribute.

Several research methods have previously been described for involving individuals with aphasia in person-centered activities, like interviews for research purposes. Interviews provide researchers with rich, detailed, qualitative data for understanding the experiences of participants and the meaning they make from their experiences [13]. However, interviewing patients with aphasia can be difficult and therefore alternative methods are often required. The use of video as a visual means of data collection [7] has been shown to be an effective method for qualitative research in health care as a means of reflection and elicitation. While Iedema et al [7] described the advantages of reviewing the video footage from a health care provider perspective, this experience was concerned with the processes and procedures within the workplace. Video ethnography has been shown to be successful for analyzing consulting methods, for remodeling within a general practice setting [8], and to help staff to reflect on their work [14]. It was also noted that the simple presence of the video camera was regarded as having a positive influence by eliciting a more reflexive work method.

Dalemans et al [9] suggested several adjustments to qualitative research techniques when working with patients with aphasia, including reducing the cognitive load by reducing the content, utilizing clear visual structure when able, and utilizing alternative forms of communication, such as pictures, writing, gestures, and mime. These methods of communication and interaction with patients with aphasia in an interview situation may provide more open and relaxed communication between the interviewer and the interviewee. These adjustments may also be in line with the rehabilitation methods utilized poststroke and might be considered familiar and less intrusive than methods such as video. Luck and Rose [15] expressed similar findings, suggesting that researchers need to “step out of their traditional role” by changing the way they ask questions, offer ideas to patients, and use various supportive conversation techniques.

Including participants with aphasia in qualitative research into stroke service redesign is important for ensuring that the provision of health care services meets the needs of all patients. The experiences of patients with aphasia in the hospital and in the community provide valuable information toward ensuring that all patients are afforded the services that they require. These participants identified that it is important to deliver assessment and communication tools and rehabilitation services that meet the specific needs of different patients with aphasia, as well as other post-stroke complications. Excluding patients with aphasia from this research would have reduced the potential sample size by about one-quarter and resulted in a huge gap in the experiential data. The focus of the interview data was not about the patients’ communication deficits, although it was expected and confirmed in some cases that communication difficulties had hindered, or at least altered, their experiences in the hospital. Without including this feedback in the co-redesign process, gaps in service provision for aphasic patients could remain.

Utilizing various methods of communication is often necessary to ensure a full and information-rich experience for both the interviewer and the interviewee, and documenting how the researcher does this and how this experience changes the interview and data collected is an important component of the inclusive, co-design methodology.

Limitations

The major limitations of this study were the small cohort of patients and the lack of information collected before the interviews about their potential communication deficits, which had a profound effect on the experience of the researchers conducting the face-to-face interviews. Without a full understanding of the needs of the participant, the research team was ill-prepared to collect useful data, which also created angst among them. Improved screening processes beforehand would have been beneficial to aid in the design of the interview and data collection methods. In the future, specific strategies, including the presence of more than one interviewer or video recording rather than audio data collection, may be useful for qualitative research participants with aphasia or other communication deficits. Research investigating the views of individuals with aphasia on the best methods for interviews would be an important step in developing patient engagement strategies for health service improvement.

Conclusion

The reliance upon the written word in the form of transcriptions of audio-recorded interviews in qualitative research reinforces the limitations of using just this type of communication. For future qualitative research that intends to engage individuals with aphasia, researchers must devise appropriate strategies and methods beforehand to maximize the contributions and valuable communications of these participants, as well as reduce the possibility for negative emotional responses in ill-prepared researchers.

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Conflicts of Interest

None declared.

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Original Paper

Relationship Between Health Literacy and Social Support and the Quality of Life in Patients With Cancer: Questionnaire Study

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Abstract

Background: Low health literacy is associated with factors such as not taking medication as prescribed as well as poor health status and increased hospitalization and mortality risk, and has been identified as a risk factor for decreased physical function in older individuals. Health literacy is becoming an increasingly important issue because of the increased number of people affected by cancer who must make complicated treatment decisions. Health literacy has been shown to be positively associated with quality of life (QOL), and social support has been identified as important for addressing health-related problems and reducing the relative risk of mortality in patients with cancer. However, few studies have examined the relationship between health literacy, social support, age, and QOL.

Objective: The aim of this study is to examine the effects of health literacy, social support, and age on the QOL of patients with cancer.

Methods: An anonymous, self-administered online questionnaire was conducted from March 28 to 30, 2017, in Japan on patients with lung, stomach, or colon cancer that were voluntarily registered with an internet survey company. The survey covered basic attributes, health literacy, social support, and QOL. The European Health Literacy Survey Questionnaire, a comprehensive measure of health literacy instrument, was used to measure health literacy; the Japanese version of the Social Support Scale was used to measure social support; and the Japanese version of the Functional Assessment of Cancer Therapy-General (7-item version) assessment tool was used to measure QOL.

Results: A total of 735 survey invitations were randomly sent to patients with lung, stomach, or colorectal cancer, and responses were obtained from 619 (82.2% response rate). Significant effects on the QOL in patients with lung, stomach, or colon cancer were observed for health literacy, social support, and age, and for the interactions of health literacy and social support and of social support and age. Health literacy, social support, and the interaction between these variables also showed a significant effect on the QOL in patients 50 years or older, but not on those younger than 50 years.

Conclusions: The results of this study revealed that higher health literacy, social support, and age were associated with the QOL in patients with cancer. In addition, the relationship with QOL was stronger for social support than for health literacy. These findings suggest the importance of health literacy and social support and indicate that social support has a greater effect on QOL than does health literacy, while the QOL in patients with cancer aged younger than 50 years was lower than that of those 50 years or older. Therefore, elucidating the needs of these patients and strengthening social support based on those needs may improve their QOL.

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KEYWORDS

health literacy; social support; quality of life; neoplasms; health communication

Introduction

Health Literacy and Quality of Life in Patients With Cancer

Health literacy is the ability to obtain, understand, evaluate, and use information about health and medical care [1]. Low health literacy is associated with poor health status, limited access to health care, increased use of expensive health care services, and high mortality rates [2-4]. In addition, it is associated with not taking medication as prescribed [5,6] as well as increased hospitalization and mortality risk in patients with a history of heart failure [7]. Among older individuals, low health literacy has been identified as a risk factor for decreased physical function [8]. Moreover, in terms of prevention, low health literacy has been found to be associated with low participation in colorectal cancer screening [9].

Increasing numbers of people worldwide are afflicted by and die from cancer [10-13]. Patients with cancer must make complicated decisions that have a major effect on their treatment and future; thus, health literacy is a particularly important issue [14]. Low health literacy can result in the misunderstanding of a disease, inadequate treatment due to the inability to communicate satisfactorily with health care personnel, and an inability to comply with treatment plans [15-17].

The World Health Organization defines quality of life (QOL) as an individual’s perception of their position in life in the context of the culture and value systems where they live and in relation to their goals, expectations, standards, and concerns [18]. Considering the continuous care required for patients with cancer, including the use of medical care services, routine health management, and end-of-life medical care, health literacy has a major effect on QOL [19-22]. In a previous study [23], health literacy was found to be positively associated with QOL.

Efforts to increase health literacy appear in national policies in the form of programs such as the National Action Plan to Improve Health Literacy in the United States [24] and The Japan Vision: Health Care 2035 [25]. However, the results have been less than satisfactory [26]. Moreover, health literacy does not increase with health care experience [27]. The findings of these previous reports suggest that improving health literacy is not a straightforward task.

Social Support and Quality of Life in Patients With Cancer

The QOL in patients with cancer has been found to be affected by the attributes and psychological and physical health of the individual [28-30], and by symptoms and levels of high anxiety after cancer treatment [31]. These factors have been found to be important in facilitating adaptation to daily life following treatment [32]. In addition, social support has been identified as an important means of addressing health-related problems [33]. A study of patients with lung cancer suggested that social and emotional support are important for QOL [34]. Moreover, strong social support has been shown to reduce the relative risk of mortality in patients with cancer [35]. A study of aged survivors of cancer found that QOL was high in individuals with strong emotional support and low in those with weak emotional support [36]. Further, in a study of aged patients with cancer undergoing chemotherapy, QOL was higher in those with strong social support [37], and in patients with colon or rectal cancer, QOL increased with stronger social support [38]. However, to our knowledge, health literacy and QOL and social support and QOL have only been studied separately; few studies have examined the relationship between health literacy and social support.

Health Literacy, Social Support, Age, and Quality of Life in Patients With Cancer

Lee (2004) [33] posed a research question on health literacy, social support, and QOL regarding whether social support can mitigate low health literacy and improve QOL. In addition, a similar study found that low health literacy and a high degree of social isolation were independently associated with increased mortality risk [39]. A high degree of social isolation and weak social support may overlap, and mortality can be understood as an objective number. The present study takes Lee’s (2004) [33] research question seriously, and in doing so, attempts to clarify the relationship between QOL and health literacy and social support in patients with cancer (research question 1).

Lee (2009) [40] examined health literacy, social support, and QOL in relation to Medicare in the United States, and found positive correlations between high health literacy, high social support, and better QOL. An examination of cancer mortality risk according to age reported that the risk of cancer mortality increases with age. According to the American Cancer Society, 80% or more of patients diagnosed with cancer in the United States are 55 years or older [41]. In the United Kingdom, the incidence of cancer rapidly increases beginning at around 55 years of age, according to Cancer Research UK [42]. In Japan, the risk of cancer for both men and women starts to increase when people are in their 50s [43]. Consequently, in addition to research question 1, this study examined the relationship between QOL and health literacy and social support in patients aged 50 years or older and patients younger than 50 years, and whether there were differences between these two groups (research question 2). This approach was based on facts that Smith et al (2018) [39] previously looked at in patients 50 years or older, and cancer risk begins to increase when people reach their 50s.

Methods

Participants

An anonymous, self-administered, online questionnaire survey was conducted from March 28 to 30, 2017, by an internet survey company in Japan. The survey participants were recruited from voluntarily registered patients with lung, stomach, or colon cancer. These types of cancer were selected because they ranked as the top three for cancer mortality in Japan [43]. In total, 735 potential respondents (diagnosed with lung, stomach, or colon cancer, and between the ages of 20-69 years) were randomly invited by email to participate in an anonymous, cross-sectional online survey, and 619 accepted the invitation and responded (collection rate 82.2%). The survey data were anonymized and managed so that individuals involved in the study could not be identified. This study was approved by the institutional review board of the University of Tokyo Interfaculty Initiative in Information Studies.

Measures

The survey covered basic attributes, health literacy, social support, and QOL. The instrument used to measure health literacy was the European Health Literacy Survey Questionnaire (HLS-EU-Q47), a comprehensive measure of health literacy. The reliability and validity of the questionnaire has been confirmed for not only the original version, but also the Japanese translation (HLS-EU-Q47 Japanese Version) [44]. The HLS-EU-Q47 is not targeted at patients with cancer, and its items can be divided into three areas: health care, disease prevention, and health promotion. Because the participants in this study were patients with cancer, the survey was narrowed to 16 health care items related to the health care experiences of patients with cancer. The items asked whether the participants were able to find information on their disease and its treatment, whether they understood the information they obtained from physicians, and whether they understood the medications they received.

To measure social support, the Japanese version of the Social Support Scale [45,46] was used. The reliability and validity of the Japanese version of the scale have been validated. The Japanese version of the Functional Assessment of Cancer Therapy-General (7-item version) (FACT-G7) version 4 assessment tool was used to measure QOL [47]. The Functional Assessment of Cancer Therapy-General (FACT-G) has been used in studies of QOL and health literacy in patients with cancer [23]. Although the FACT-G7 is an abbreviated version of the established FACT-G, its effectiveness has been confirmed to be interchangeable with that of the FACT-G [48]. The FACT-G7 was used in this study to minimize the burden on the survey participants.

Analysis

For health literacy, responses to the 16-item Japanese version of the HLS-EU-Q47 questionnaire were obtained as a score of 1 to 4 points on a 4-point Likert scale (from very easy to very difficult, reverse-scored items) or 0 (do not know). For social support, responses to the 12-item Japanese version of the Social Support Scale were obtained as a score of 1 to 5 points on a 5-point Likert scale (from disagree to agree). Responses to the 7-item Japanese version of the FACT-G7 (version 4) were obtained as a score of 1 to 5 points on a 5-point Likert scale (from very much to not at all). Reverse-scored items were adjusted so that 5 indicated a high QOL and 1 indicated a low QOL. The mean score for the seven items was used for QOL. All the variables of each construct were calculated as the sums of the item scores.

A multiple regression analysis performed with QOL as the dependent variable used age, sex, household income, educational level, time since diagnosis, type of cancer, and disease stage as dummy variables when the survey was conducted, and the standardized values (z scores) of the total score for the 16 health literacy items and the total score for the 12 social support items were used as independent variables. Statistical analysis was performed using SPSS version 24 (IBM Corp, Armonk, NY) and R 3.6.1 software (R Foundation for Statistical Computing, Vienna, Austria).

Results

Participants

The characteristics of the survey participants are shown in Table 1. The mean health literacy, social support, and QOL values were 2.25 (SD 0.71), 3.52 (SD 0.94), and 3.41 (SD 0.80), respectively. Dividing the participants into two groups based on age, the values were 2.29 (SD 0.67), 3.63 (SD 0.92), and 3.66 (SD 0.78), respectively, for those aged 50 years or older and 2.19 (SD 0.78), 3.35 (SD 0.95), and 3.05 (SD 0.69), respectively, for those younger than 50 years.

Table 1. Characteristics of the survey participants.

Characteristics	Total (N=619), n (%)	Age ≥50 years (n=376), n (%)	Age <50 years (n=243), n (%)
Sex			
Male	477 (77.1)	317 (84.3)	160 (65.8)
Female	142 (22.9)	59 (15.7)	83 (34.2)
Household income (million JPY)			
<4	157 (25.4)	107 (28.5)	50 (20.6)
≥4 and <8	209 (33.8)	123 (32.7)	86 (35.4)
≥8	178 (28.8)	110 (29.3)	68 (28.0)
Unknown or not available	75 (12.1)	36 (9.6)	39 (16.0)
Educational attainment			
Less than university degree	253 (40.9)	159 (42.3)	94 (38.7)
University/graduate degree	354 (57.2)	208 (55.3)	146 (60.1)
Other or unknown	12 (1.9)	9 (2.4)	3 (1.2)
Time since diagnosis			
<6 months	99 (16)	51 (13.6)	48 (19.8)
≥6 months and <1 year	82 (13.2)	42 (11.2)	40 (16.5)
≥1 year and <2 years	182 (29.4)	113 (30.1)	69 (28.4)
≥2 years	256 (41.4)	170 (45.2)	86 (35.4)
Site of primary tumor			
Lung	119 (19.2)	57 (15.2)	62 (25.5)
Stomach	206 (33.3)	124 (33.0)	82 (33.7)
Colon	294 (47.5)	195 (51.9)	99 (40.7)
Cancer stage			
I	250 (40.4)	151 (40.2)	99 (40.7)
II	133 (21.5)	65 (17.3)	68 (28.0)
III	103 (16.6)	64 (17.0)	39 (16.0)
IV	50 (8.1)	32 (8.5)	18 (7.4)
Unknown	83 (13.4)	64 (17.0)	19 (7.8)

Quality of Life in Patients With Cancer

A multiple regression analysis including dummy variables was performed with QOL as the dependent variable, and the model shown in Table 2 was obtained ($F_{22,596}$=811.99; P<.001; adjusted R^2=0.281). In this model, the standard partial regression coefficients were significant for age, health literacy, social support, interaction of health literacy and social support, and interaction of social support and age.

Table 2. Multiple regression analysis of quality of life for all participants.

Variables	B	SE	Beta	*P* value	Variance inflation factor
(Constants)	3.453	0.110	N/A[a]	<.001	N/A
Female (reference male)	0.105	0.070	.055	.13	1.140
Age ≥50 years (reference <50 years)	0.526	0.061	.320	<.001	1.184
Household income ≥4 and <8 million JPY (reference <4 million JPY)	–0.040	0.074	–.024	.59	1.637
Household income ≥8 million JPY (reference <4 million JPY)	–0.026	0.079	–.015	.79	1.704
Household income unknown or not available (reference <4 million JPY)	–0.187	0.098	–.076	.06	1.373
University/graduate degree (reference less than university degree)	0.035	0.060	.022	.55	1.158
Other/unknown (reference less than university degree)	0.112	0.208	.019	.59	1.101
Time since diagnosis ≥6 months and <1 year (reference <6 months)	–0.111	0.104	–.047	.29	1.657
Time since diagnosis ≥1 and <2 years (reference <6 months)	0.086	0.087	.049	.32	2.100
Time since diagnosis ≥2 years (reference <6 months)	–0.006	0.083	–.003	.95	2.244
Stomach cancer (reference lung cancer)	0.016	0.081	.010	.84	1.940
Colon cancer (reference lung cancer)	0.199	0.078	.124	.01	2.019
Stage II (reference Stage I)	–0.301	0.075	–.154	<.001	1.266
Stage III (reference Stage I)	–0.237	0.082	–.110	.004	1.242
Stage IV (reference Stage I)	–0.622	0.109	–.211	<.001	1.167
Stage unknown (reference Stage I)	–0.020	0.090	–.008	.82	1.254
Health literacy	0.106	0.029	.132	<.001	1.106
Social support	0.169	0.029	.210	<.001	1.096
Health literacy * Social support	–0.050	0.025	–.073	.047	1.139
Health literacy * Age	0.069	0.057	.043	.23	1.084
Social support * Age	0.196	0.057	.119	.001	1.039
Health literacy * Social support * Age	–0.082	0.048	–.061	.09	1.126

[a] N/A: not applicable.

Quality of Life According to Age

A multiple regression analysis including dummy variables was performed for individuals aged 50 years or older with QOL as the dependent variable, and the model shown in Table 3 was obtained ($F_{18,357}$=7.33; P<.001; adjusted R^2=0.233).

In this model, the standard partial regression coefficients were significant for health literacy, social support, and the interaction between health literacy and social support.

The results of a simple slope analysis for the interaction of health literacy and social support are shown in Table 4 and Figure 1. For health literacy and social support, a value below the mean was considered low, and a value equal to or above the mean was considered high.

A significant association was seen between QOL and social support, regardless of the level of health literacy (P<.001). However, the coefficient for social support was larger when health literacy was low compared with when it was high.

Next, a multiple regression analysis including dummy variables was performed with QOL as the dependent variable for participants younger than 50 years; the results were not significant ($F_{18,224}$=1.63, P=.06).

Table 3. Multiple regression analysis of quality of life in patients aged 50 years or older.

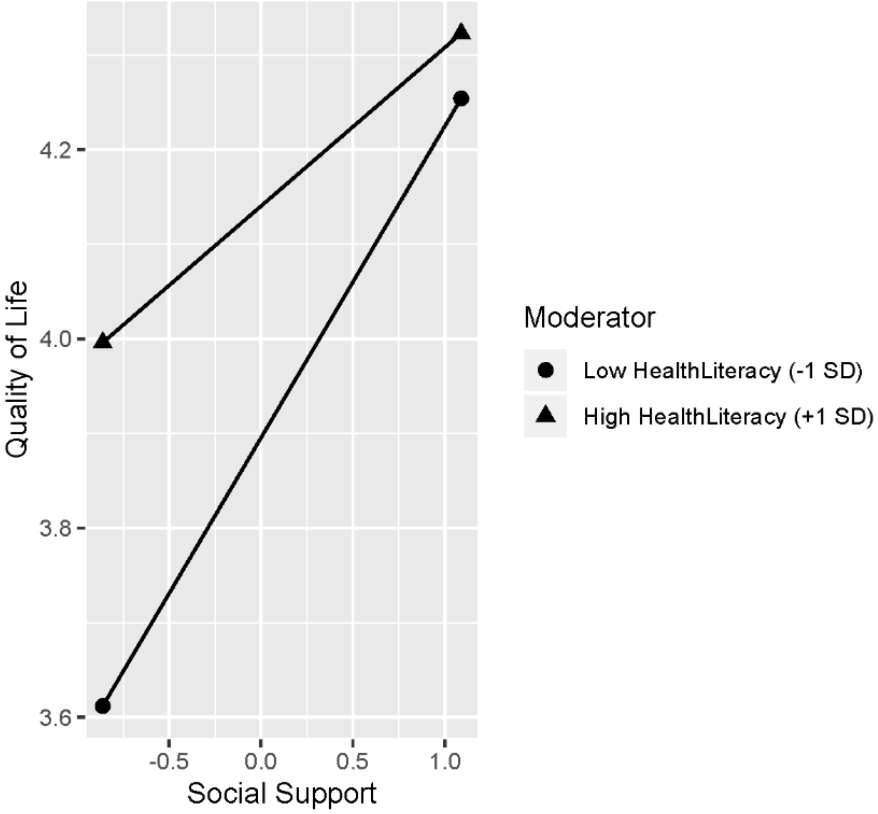
Variables	B	SE	Beta	*P* value	Variance inflation factor
(Constant)	3.647	0.150	N/A[a]	<.001	N/A
Female (reference male)	0.094	0.103	.044	.36	1.115
Household income ≥4 and <8 million JPY (reference <4 million JPY)	–0.110	0.094	–.066	.24	1.541
Household income ≥8 million JPY (reference <4 million JPY)	–0.059	0.099	–.034	.56	1.617
Household income unknown or not available (reference <4 million JPY)	–0.388	0.135	–.146	.004	1.255
University/graduate degree (reference less than university degree)	0.059	0.078	.037	.45	1.204
Other or unknown education (reference less than university degree)	0.068	0.245	.013	.78	1.120
Time since diagnosis ≥6 months and <1 year (reference <6 months)	–0.071	0.148	–.028	.63	1.737
Time since diagnosis ≥1 and <2 years (reference <6 months)	0.093	0.118	.055	.43	2.354
Time since diagnosis ≥2 years (reference <6 months)	0.067	0.113	.043	.55	2.522
Stomach cancer (reference lung cancer)	0.089	0.113	.053	.43	2.256
Colon cancer (reference lung cancer)	0.276	0.108	.176	.01	2.324
Stage II (reference Stage I)	–0.431	0.105	–.208	<.001	1.254
Stage III (reference Stage I)	–0.251	0.107	–.121	.02	1.279
Stage IV (reference Stage I)	–0.697	0.138	–.249	<.001	1.180
Stage unknown (reference Stage I)	–0.121	0.107	–.058	.26	1.294
Health literacy	0.125	0.039	.150	.002	1.087
Social support	0.246	0.038	.306	<.001	1.093
Health literacy * Social support	–0.083	0.036	–.109	.02	1.085

[a] N/A: not applicable.

Table 4. Simple slope analysis for interaction of health literacy and social support.

Variables	Simple slope	SE	t_{357} (2-tailed)	*P* value
Low health literacy (–1 SD)	0.33	0.05	6.56	<.001
High health literacy (+1 SD)	0.17	0.05	3.34	<.001

Figure 1. Relationship between health literacy and social support and the quality of life in patients 50 years or older.



Discussion

Relationship Between Health Literacy and Social Support and the Quality of Life in Patients With Cancer

We identified significant effects of health literacy, social support, age, interaction of health literacy and social support, and interaction of social support and age on QOL for the patients with lung, stomach, or colon cancer. We also found that the effect of social support and age is stronger than that of health literacy when controlling for the effects of other independent variables. In addition, health literacy, social support, and their interaction were found to have a significant effect on QOL. Moreover, the effect of social support is stronger for low health literacy than for high health literacy in those 50 years or older, while there is no effect on the QOL in those younger than 50 years.

Studies involving patients with cancer have indicated that health literacy with respect to treatment is important for understanding a disease [14-16], and that health literacy is positively associated with QOL [23]. Previous results on social support have indicated that among older patients with cancer undergoing chemotherapy, QOL was higher for those with strong social support [37]. In this study, the levels of health literacy and social support were related to QOL. Moreover, the association was stronger for social support than for health literacy. These findings suggest that both health literacy and social support are important considerations for the QOL in patients with cancer.

Health literacy can be considered a patient resource [49]. Although efforts have been undertaken to increase health literacy, this is not easily accomplished [24-26]. Social support, on the other hand, is a resource provided by the people with whom the patient associates. Support from family members, friends, and acquaintances is what the patient is most familiar with, and thus, it is important to continue to strengthen such support. However, this support varies depending on the individual, and those providing support may have their own physical, emotional, social, or financial problems [50]. Consequently, a need for consulting services that specialize in social support has been suggested [51].

Efforts to provide a system of social support not dependent on individual circumstances have been implemented. Maggie’s [52] centers were first established in Edinburgh in 1996. These centers provide free practical, emotional, and social support to patients with cancer and their friends and family members. There are currently 20 such centers in the United Kingdom (mainly in National Health Service cancer hospitals) and other countries, and an online center has been established. Because the centers are places that anyone can casually visit at any time, it is difficult to maintain records for each individual and measure the effectiveness of the centers. However, the results of this study indicate that although it is difficult to increase health literacy, an individual resource, improving social support may lead to increased QOL in patients with cancer. This reinforces the importance of efforts to improve and facilitate social support.

Quality of Life, Health Literacy, and Social Support According to Age

Studies in older individuals have shown that QOL increases with health literacy and social support. This study showed similar positive associations between QOL and health literacy and social support in patients with cancer 50 years or older. Moreover, the association was stronger for social support than for health literacy. A negative association was observed with the interaction of health literacy and social support, but the coefficient was much lower than for health literacy and social support. Patients high in health literacy collect information actively and independently and come to conclusions based on that information. The information and support provided by people around the patient may be at odds with those conclusions. In that case, the patient may become confused by the discrepancy and not amenable to social support. A simple slope analysis of the interaction between health literacy and social support showed social support to be significantly associated with QOL regardless of the level of health literacy. However, the coefficient for social support was larger when health literacy was low than when it was high. This result differs from the finding that, in older individuals, social support was more positively associated with health in those high in health literacy [40]. This may be related to the fact that the participants in this study were patients with cancer. The finding that social support was more positively associated with QOL in patients with cancer 50 years or older with low health literacy may be explained as follows: increasing the social support of patients with cancer that have low health literacy can mitigate the negative effect of low health literacy on QOL, as was indicated in the 2004 report by Lee [33].

The results for patients with cancer younger than 50 years differed from patients with cancer 50 years or older. Studies in young patients with cancer have included those of the adolescents and young adults (AYA) generation. The QOL in the AYA generation patients with cancer has been found to be low [53-57]. Moreover, the financial, mental health, and support group services available for the AYA generation patients are inadequate [58-60], as these patients desire information on side effects, alternative treatment options, pregnancy and childbirth options, and long-term care [59,61,62]. The AYA generation patients have also been shown to fear a continual fight against cancer and to experience negative emotions related to financial problems, death, body image, and perceived stigmas [62,63]. Furthermore, the types of treatment, lack of insurance, and withdrawing from school or a job after diagnosis have negative effects on occupational and educational outcomes [63,64]. Relationships with friends, family members, and other cancer survivors have been shown to lead to improved QOL in the AYA generation patients [60,62]. However, siblings of these patients have been reported to experience high levels of psychological distress [65], and problems such as persistent negative emotions related to the diagnosis and stigma associated with cancer have been reported for the parents and caregivers of such patients [66]. Thus, it may be difficult for patients with cancer to receive adequate support from family members, who are the patients' closest supporters.

Similar to the AYA generation, patients younger than 50 years are affected by cancer early and must therefore cope with the disease for a long time, making the mental burden greater than that of patients aged 50 years or older. Because there are generally few patients with cancer in the same age group, it will be important to examine further ways to strengthen the social support system based on their needs.

Limitations

This retrospective study was conducted using an online survey. Consequently, a limitation of the study was that it was based on patient perceptions. Further investigations that consider factors such as the type and stage of cancer and the time since diagnosis are needed for young patients. Accordingly, it will be important to examine how to strengthen the support systems available to patients with cancer by elucidating their needs based on their current status.

Conclusions

The results of this study showed that the QOL in patients with cancer increased with health literacy, social support, and age. Moreover, the relationship with QOL was stronger for social support than for health literacy; similar results were obtained for patients with cancer 50 years or older. These findings suggest the importance of health literacy and social support, which has been noted previously, and indicate that the support of those around the patient has a greater effect on QOL than health literacy.

Different results were obtained for patients with cancer younger than 50 years. QOL in this group was lower than that in those 50 years or older. In view of the problems faced by younger patients with cancer, which have been identified in previous studies, elucidating the needs of these patients and further strengthening social support based on those needs may lead to improvements in QOL.

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Conflicts of Interest

None declared.

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Abbreviations

AYA: adolescents and young adults
FACT-G: Functional Assessment of Cancer Therapy-General
FACT-G7: Functional Assessment of Cancer Therapy-General (7-item version)
HLS-EU-Q47: European Health Literacy Survey Questionnaire
QOL: quality of life

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