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When great responsibility comes with limited options: experiences and needs of older community-dwelling adults regarding accessing, understanding, appraising and using health-related information

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Abstract

Background In previous research, older adults have been associated with reduced levels of health literacy (HL) influenced by a range of contextual factors. To optimise HL, it is essential to better understand the interactions between the ageing process and both personal and environmental factors as perceived by older adults. This study aimed to explore the experiences and needs of older community-dwelling adults when accessing, understanding, appraising and using health-related information.

Methods An explorative, qualitative design was used within the social constructivism framework. Semi-structured individual interviews were conducted with 20 adults aged 70–96 living at home in three areas in Northern Iceland. The transcribed interviews were constructed into categories and subcategories using qualitative content analysis. Findings.

Four categories emerged. “Expectations for responsibility” describes the experience that individuals are responsible for taking care of their health, including accessing, understanding, appraising and using information and services, showing initiative and keeping needed communications active. “A gap between expectancy and ability/context” includes experiences while taking responsibility for expectations not aligning with skills/situations, creating information gaps. “Finding one’s own ways” comprises various adapted ways to access, understand, and use information and services. “Bridging the gap” describes experiences of needing shared responsibility and more manageable options to enable reasoned health-related decisions and navigation in the healthcare system.

Conclusions The participants valued and took full responsibility for accessing, understanding, appraising and using information and services as part of a social norm; however, they experience information gaps. They request shared responsibility by being provided with fundamental health-related information as a vital step in making reasoned health-related decisions and navigating the healthcare system. They also request more inclusive and accessible service opportunities to bridge the gaps and facilitate HL. It is necessary to critically address, at a systematic level, the conflict between expected individual responsibility and the existence of options to act upon this responsibility.

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In matters of health, health services and HL, the need to analyse and confront structural disadvantages experienced by older adults is highlighted.

Keywords Access to health care, Access to information, Ageing, Health literacy, Health promotion, Information seeking behaviour, Qualitative research

Introduction

Health literacy (HL) refers to both the personal skills and social resources needed for individuals and communities to access, understand, appraise and use information and services to make reasoned health-related decisions and to navigate in the healthcare system [1, 2]. HL is therefore considered essential to maintaining and improving quality of life throughout the life course [3]. With advancing age, older adults may require more frequent interactions with health-related information. Consequently, the importance of addressing HL concerning older adults has been emphasised [4], particularly because of population projections that indicate a global increase in the number of older adults in the future and the need to enhance health promotion for this group [5].

In Europe, an effort has been made to measure HL levels, for example, with the European Health Literacy Survey Questionnaire (HLS-EU-Q), among the general population. Limited HL is associated with social and socioeconomic conditions, particularly lower levels of education, income, low social status and older age [4, 6–8].

Acknowledging HL as an interaction of individual skills within a social context, it is essential to look beyond the personal level and include the social structures in which people live. That is, to better understand the influence of the situations in which people are required to use their HL skills and capabilities [9, 10]. There is, for example, a heightened focus on the organisational context of HL, the health system's demands and the complicated information environment in a modern world [11, 12]. However, at the same time, it is essential to recognise the complexity of the social context of HL [9, 10]. This has, for example, been addressed in research focusing on experiences related to health information among socioeconomically disadvantaged adults in Switzerland [13], among refugees in Sweden [2] and as part of information literacy in everyday life among people aged 47–64 [14] and 57–70 in Australia [15].

Research findings concerning older adults in Iceland echo this complex interaction between the ageing process, HL and both personal and environmental factors. Notably, HL has been connected to the personal factors of age in years, education level, income, resilience and depression and the environmental factors of means of transport and perceived access to healthcare and medical

service [16]. These factors seem to play an important role in HL; however, further information is needed to comprehensively understand this dynamic interaction between older adults, HL and their context. In contrast to using quantitative measurements in relation to HL as is prominent, a qualitative perspective is needed to gain a deeper understanding of the matter. Therefore, this study aimed to explore the experiences and needs of older community-dwelling adults concerning accessing, understanding, appraising and using health-related information.

Methods

Study design

This qualitative study within the social constructivism framework sought to understand the specific contexts in which people live [17, 18]. An explorative design was used to find and create knowledge of the focused and little-studied phenomena [19]. We conducted individual semi-structured interviews to generate qualitative data, get insights into the lives of older adults and establish knowledge [20].

The research group consisted of three Icelandic researchers (SSG, SAA and AKS), a Swedish (LM) researcher and an Icelandic senior citizen (AS). The four researchers created an interdisciplinary team of occupational therapists (SSG and LM), a physiotherapist (SAA) and a nurse (AKS) as professors/researchers (LM, SAA and AKS) and a PhD student (SSG). The group's expertise, research and lived experience lie within ageing, daily living, gerontology, HL, health promotion, qualitative research and urban/rural settings.

This study is reported following the Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist [21]. An application for ethical approval was sent to the Icelandic National Bioethics Committee. The committee deemed permission not necessary according to Icelandic law on scientific research in health (VSN-21–009 based on VSNb2016060007/03.01).

Participants and setting

Participants in this study were purposefully selected from 175 partakers in a previous quantitative cross-sectional study on HL. That study was based on a stratified random sample from the national register of community-dwelling

people 65 years and older in one urban town and two rural areas in Northern Iceland [16, 22].

To get as broad a perspective as possible, the selection criteria for this study were based on the aim of interviewing older people with various backgrounds regarding place of living, age, gender, education, means of transport and distance from services. The selection procedure was conducted in three steps, as shown in Table 1. In the first step, potential participants were sorted by partakers' numbers from the previous quantitative research. They were placed into a matrix list based on five to six determining factors, with a sixth factor being considered for those living in rural areas. Considering the amount of needed information, that some people might not be reached and some might decline participation, the matrix list included 69 from 175 previous partakers, with many categorised with the same factors. In the second step, previous partakers' numbers and the names of potential participants were connected. Information recorded at the Register Iceland database on a) social security number, b) place of living and c) a registered telephone number accessible through an open website were matched. This information could not be paired for 21 persons, leaving 48 on the potential participants' list. In the third and last step, 20 people on the list were contacted for participation. They all agreed, consented, and were subsequently interviewed.

All participants, 11 women and nine men were born and raised in Iceland except for one individual who, despite not being native, had resided in the country for decades. Their birth years ranged from 1926 to 1952, and the median age was 76,6 years. Seven had elementary education, eight a secondary or trade school education and five a university degree. Agriculture, education, trade, healthcare and homemakers were the main occupation fields.

In three interviews, the spouse was present. In one case, the participant had early-stage Alzheimer's, so in cooperation with the couple, it was decided that the

spouse would play the roles of support, memory and voice. In the other two cases, both in rural settings, the spouse of the participant was present in the kitchen, where the interview was conducted as a part of the culture in place. The spouses were not direct participants in the interview; however, they added information when, for example, asked to recall a process, names or times.

Procedure

Potential participants were sent an invitational letter by mail and subsequently contacted (by SSG) by telephone and invited to participate. Data were collected over one year, from January 2022 to January 2023. SSG conducted all of the interviews in Icelandic at the participants' chosen place. The interviews were audio-recorded and lasted from 30 to 65 min, with an average of 46 min. The recordings were deleted after transcription. An interview frame designed for this study was used, which included a) opening questions about the length of time living in their current area, main occupation and preferred pseudonyms for confidentiality; b) questions about HL, which asked the participants to describe their experience of accessibility, clarity and usefulness of health-related information and services; and c) an opportunity to add any information.

Data analysis

The interviews were transcribed verbatim and analysed using content analysis as described by Graneheim and Lundman [23] and Graneheim, Lindgren and Lundman [24]. The method offers researchers different epistemological positionings with various levels of abstraction and degrees of interpretation, depending on the study aim and data quality. It is, for example, applicable when knowledge is believed to be socially constructed [24]. As reflexivity was considered an essential part of the whole process, the analysis was conducted with a team of all authors. Although SSG and LM mostly did the main work because of their pre-understanding of the research

Table 1 Participants' main selection procedure

		Urban town	Rural area 1	Rural area 2	Total
Previous study partakers:		105	33	37	175
Step 1	Matrix factor list: ^a				
	Selected	33	18	18	69
Step 2	Necessary contact information:				
	Available	20	15	13	48
Step 3	Contacted:				
	Accepted and interviewed	10	5	5	20

^a Matrix list included the following factors: 1) urban/rural place of living (by zip codes), 2) age groups (70–74, 75–84, 85–89, 90+), 3) gender (female, male), 4) education (elementary, secondary/trade school, university degree), 5) means of transport (walk, drive on own, driven by others, public transport) and 6) distance from healthcare service in rural areas (0–5, 5–20, 20 + km)

area and the method used for analysis, all the authors met in working meetings at each step of the analysis process, as described below. These meetings were used for reflection on the empirical data, the potential influence of preconceptions and the emerging findings from SSG and LM. In addition, a reflection from AS with a lived experience of the matter was sought in each step. Throughout the analysis process, work was carried out in Icelandic and English. Transcriptions were entered into the data management software NVivo 11 [25] for data storage, organisation, and coding. However, the team encountered difficulties in sharing information using the software, which resulted in the analysis being conducted manually in a Word document.

In the first step, all the authors read the interviews several times to understand the content. The three Icelandic researchers read the material in their native tongue, and the Swedish researcher used an English Google-translated version. The interviews were discussed both as a whole and in specific parts, where meaning units and potential content areas in consideration of the study's objective were identified.

In the second step, meaning units were identified according to the aim of the study and condensed into descriptions close to the text, preserving the core meaning, abstracted and labelled with codes. Further abstraction occurred as subcategories and categories emerged from the condensed content based on patterns or commonalities. Similarities, differences and connections between and within the content were reflected upon and sorted. Constant comparison was used to clarify meanings, comparing data with codes and codes with codes.

In the third and last step, further analysis took place when the descriptive content of the preliminary categories was formulated by going back and forth and checking consistency between the categories, their content and the empirical data. The emerged core meanings were validated by contextualizing the meaning units in the individual interviews and the data as a whole. The 20 interviews provided insightful data to answer the purpose of the study, which was to explore the experiences and needs of older community-dwelling adults concerning accessing, understanding, appraising and using health-related information.

Findings

Based on manifest content, four qualitative categories emerged from the experiences and needs of older community-dwelling adults. Each category is independent, yet interconnected with the others, as shown in Fig. 1. "Expectations for responsibility" describe the experience that the individual should be responsible for taking care of their own health, including accessing, understanding,

appraising and using information and services, as well as showing initiative and keeping needed communications active. "A gap between expectancy and ability/context" includes experiences while taking responsibility for expectations not aligning with one's own skills/situations. "Finding one's own ways" comprises various adapted ways to access, understand, appraise and use information and services due to a misalignment between expectations for responsibility and the individual's ability or context. "Bridging the gap" describes experiences of needing shared responsibility and more manageable options to optimise reasoned health-related decisions and navigation through the healthcare system. Significant quotations are provided to illustrate the empirical foundations of the subcategories. Table 2 provides information about the manifest content from the analysis.

Expectations for responsibility

This category describes participants' experiences regarding the predominant expectation that each individual should carry the responsibility of taking care of their own health, including accessing, understanding, appraising and using health-related information as well as showing initiative and keeping needed communications active. The category is divided into two subcategories based on how this expectation is described: directly from the person and indirectly from the information providers. The subcategories were named "Personal expectations" and "Environmental expectations".

Personal expectations

This subcategory describes the experience that the person was expected to be responsible for their health and health-related matters—that is, to be their own health manager. The person should know best what they need and therefore be responsible for achieving, understanding, appraising and using information. This expectation was accepted as part of being independent and acknowledging the increase in general knowledge, making people more educated about health matters. By not taking responsibility as one's health manager, opportunities for health and welfare information might be lost, and then the person would be the only one to blame.

"You get the information you need, you just look for it... so you have nothing to complain about but yourself" (if you have missed information) (Thorunn, 76-year-old woman).

Environmental expectations

The responsibility for taking care of one's own health was also experienced as an unspoken expectation from health-related information and service providers, who

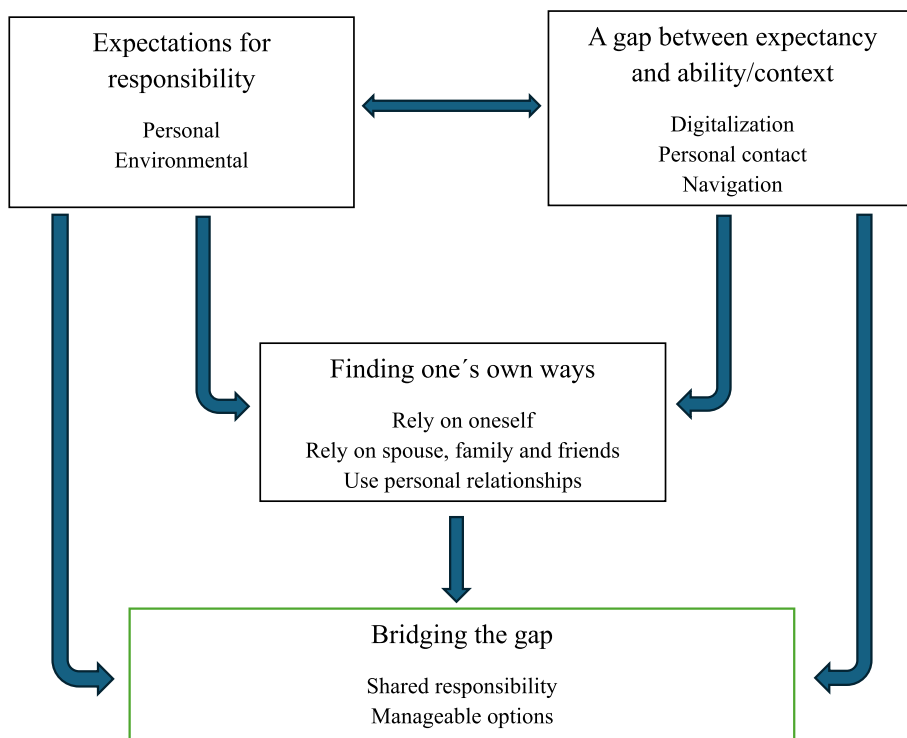


Fig. 1 Interplay of categories and subcategories for older adults' experiences and needs related to health literacy. The figure shows the interaction and tension between the categories "Expectations for responsibility" and "A gap between expectancy and ability/context" that together create limited options and push for individual action in "Finding one's own ways" when accessing, understanding, appraising, and using health-related information. Jointly, these three categories, including their subcategories, call for needed actions in "Bridging the gap", presented in the green box

Table 2 Participants' main selection procedure

Category	Expectations for responsibility	
Subcategory	Personal expectations	Codes Own health manager, My responsibility, I should know, Missing information is my fault
	Environmental expectations	Have to request, Seek and ask, Not receive, Show initiative, Information is out there
Category	A gap between expectancy and ability/context	
Subcategory	Digitalisation gap	Codes Technology skill wall, No access, Information gets lost, Lack of instructions and support, Equipment, Maintenance, Expensive
	Personal contact gap	On my own, No one knows me, Unsafe, Lost
	Navigation gap	Complicated, Disconnection, Give up, Tiering, Service not for me
Category	Finding one's own ways	
Subcategory	Rely on oneself	Codes Prior experience, Former work, Taking care of own parents
	Rely on support from spouse, family and friends	Spouse essential as manager, Necessary help from children and grandchildren, Support from friends
	Use personal relationships within welfare systems	No other way, Easier and more effective, Staff decision, Informal way
Category	Bridging the gap	
Subcategory	Shared responsibility	Codes First I need to know, What is valid, My rights
	Manageable options	Don't just tell me – enable me, Overview of service, Things important to me, More possibilities and choice, In-person support, Quality guarantee

often only deliver information if requested. In these circumstances, the individual needs to take the initiative to look for the information and services that are needed and relevant on each such occasion. If opportunities to manage one's own health were lost, this was because of a lack of responsibility of the persons rather than the information provider.

"I did not know... usually it is the case that you have to look for information" (Kara, 70-year-old woman).

A gap between expectancy and ability/context

This category describes participants' experiences of being unable to live up to the expectations of being responsible for accessing, understanding, appraising and using health-related information to manage their health. The category is divided into three subcategories based on descriptions of different kinds of gaps between the expectancy and one's own ability/context, although often interlinked, which are named "Digitalisation gap", "Personal contact gap", and "Navigation gap".

Digitalisation gap

This subcategory describes the experiences of being unable to access and use information as expected and navigating within and between the health and welfare systems because of the increased use of computers and the internet, that is, digitalisation. Although digital development was generally viewed positively, it was expressed that all the changes were happening so fast, leaving many unable to keep up. For those needing more than general information or not having all the proper equipment or the ability, digital technologies were creating a significant gap in information and services.

"You know, I am back from ancient times. I have no computer and no phone to Google and nothing, so I am completely... so many things that you cannot do unless you have a computer... all the information" (Dora, 96-year-old woman).

Personal contact gap

With the increased use of digital technology, there was also the experience of a decrease in personal and direct contact. This combination created an even wider gap between expectations of taking responsibility and one's own ability/context. This gap consisted of being unable to use entirely the formal digital ways to access, understand, appraise and use information and, simultaneously, the conventional and valued forms of person-to-person contact being limited. Being without a key person within the health and welfare systems to contact was described as being lost and not knowing what information to look for, where and what options were current or applied to them.

This contact with a key healthcare person was significant in the case of illnesses. Although generally satisfied with hands-on service, with no one knowing the health history and situation of the older person or the possibilities in the service system, there was no way to safely navigate or coordinate the necessary information and actions when needed.

"... I need to get someone I trust. I do not want to end up with a new person in every conversation and say the same thing over and over and over again. After the fifth time, you think 100 times over whether to call again... Everyone wants to assist you, but can't because they do not know you" (Hanna, 80-year-old woman).

Navigation gap

A gap in navigation while taking responsibility for accessing, understanding, appraising and using health-related information was experienced as a result of the general complexity within and between health-related services, particularly in knowing what information to find and where. This gap in navigation was fuelled by the digitalisation gap and the personal contact gap. The existence of long, complicated, and unclear communication channels, disconnection between organisations, and unclear service provision or division between entities, such as the local municipality and the state, often result in difficulties finding information or some information getting lost along the way. These were expressed as daunting, never sure of being on the right navigation course, always showing initiative and only relying on persistence not to give up. Perceived by participants as confusing, health-related service systems were described as not being made for the older service user and made to drive them away.

"...this is uncomfortable because you sometimes get the impression that the system does not care... and then you think you are somehow alone if something happens. Why isn't it better? Maybe that is why senior citizens get the impression that you are a bit set aside. It is tiring always to have to push yourself somehow through" (Sigrun, 78-year-old woman).

Finding one's own ways

This category describes the experiences of finding one's own ways to live up to the expectancy of being responsible for accessing, understanding, appraising and using health-related information. It is divided into three subcategories based on descriptions of the different ways used to adapt: "Rely on oneself", "Rely on spouse, family and friends", and "Using personal relationships".

Rely on oneself

This subcategory describes the experience of relying on oneself while managing health-related information. It was described as using knowledge through former work experience from the health and welfare service, watching parents age or even taking care of them and building on information and service from that time. Having some idea about what service is available and where to start looking for further information was expressed. This includes having enough knowledge to know where to look for information and how the services operate, given that little has changed.

“I know the operation (at the former workplace) well enough that I would look for the service, if I needed home care or something like that, I know how to do it” (Nina, 80-year-old woman).

Rely on spouse, family and friends

Finding one's own ways based on the experience of relying on the spouse, family and friends regarding health-related information was described. In situations in which the participant could not use computer technology fully or at all, but the spouse could, he or she was valued as essential and even the reason for being able to live in place. Help from grown-up children or acquaintances was also mentioned, and they considered themselves lucky to have people around to help, stating that this was not the case for everyone.

“Our daughter ... is extremely good at helping. I do not know what we would do if we lost touch with her” (Fannar, 72-year-old man).

Experiences of getting information about available services and where to turn in need at gatherings organized by local senior non-governmental organisations (NGOs) were also described. Also, when getting together, friends shared information on where to turn in need and hands-on experiences.

Use personal relationships

Finding one's own ways by using personal relationships or acquaintances with health and welfare professionals was described by some as being, at times, necessary to access information or services by using this kind of relationship. This required using informal methods rather than formal ones when no other means seemed possible.

“He (the general practitioner) was always on vacation or busy or not reachable ... so I called my son (who is a medical doctor) and said now you have to help me” (Dora, 96-year-old woman).

Others described it as a common way to use personal connections regarding health-related information, especially in rural areas where “everybody knows everyone”. Considerations of being very lucky to have this kind of relationship and being able to use this informal way were expressed.

Bridging the gap

This category describes the experience of what is needed to access, understand, appraise and use health-related information to be more able to take care of one's own health. It is divided into two subcategories based on descriptions of different needs: “**Shared responsibility**” and “**Manageable options**”.

Shared responsibility

This subcategory describes the experience of needing shared responsibility by being provided with the necessary fundamental health-related information. Although accepting the expectations of being responsible for achieving information as a part of taking care of their own health (category “Expectations for responsibility”) the experience also revealed that to do so, fundamental knowledge of what information and services exist and are current is required. To find information about services, the person first needs to know what opportunities and resources are available.

“I really expect this (information) to be handed to me when I reach the age, but not that I have to run after it” (Hanna, 80 year-old woman).

Some of the fundamental information on health-related matters was described as being provided by local senior NGOs and highly valued as such; however, at the same time, it was questioned who should be responsible for providing older adults with this information.

Manageable options

In addition to needing the provision of fundamental health-related information to bridge the gap, this subcategory describes the experience of what kind of information access is required and in what way accessed. Manageable options refer to an accessible overview of opportunities and resources that are available and current, both locally and nationwide. A clear venue for quality and reliable information is necessary, which was possible during the COVID-19 pandemic, so there is a precedent. Also, getting valuable and more relevant information is needed.

“Why do you always have to be in such a terrible shape to get information and service? ... I think there needs to be a little more about everyday things. If

you're taking care of yourself, advice is needed on the best way to do this" (Nina, 80-year-old woman).

Access to information and services must align with diverse abilities/contexts. More options than mainstream digitalisation to access information and navigate through service systems need to be available. In rural areas, experiences of information being delivered more according to the ability and context of people were described, however, as being more the personal decisions of the staff rather than an embedded system ideology. Manageable options also include offering in-person support for those who require more introduction, instructions or assistance when accessing, understanding, appraising and using information.

Discussion

The findings of this study among community-dwelling older adults revealed four separate, but interconnected, qualitative categories. The category "Expectations for responsibility" describes the experience that the person, the individual, should be responsible for taking care of their health, including accessing, understanding, appraising and using information and services. However, difficulties in doing so are revealed in the category "A gap between expectancy and ability/context" and include experiences, while taking the responsibility of expectations to do so are not in line with skills/situations. The consequences are information gaps that arise. The category "Finding one's own ways" comprises various adapted ways to access, understand, appraise and use information and services. Although accepting the expectations that the individual should be responsible for taking care of their health, the category "Bridging the gap" describes experiences of needing responsibility to be shared and more manageable options to optimise reasoned health-related decisions and navigation in the healthcare system.

The category "Expectations for responsibility" is the base for the categories "A gap between expectancy and ability/context" and "Finding one's own ways". It describes the responsibility that participants experience in accessing, understanding, appraising and using health-related information and services as part of being their own health managers. This view is fuelled by and intertwined with personal expectations and messages from the environment that seem to be a part of social norms. This experience echoes, in a way, neoliberal ideology, with its economic and political focus on individualism and autonomy. It includes the idea that people should have the right and responsibility to make their own choices, which inevitably shapes healthcare delivery systems [26, 27]. Reflecting this upon Iceland, although generally considered a part of the Nordic welfare states, the

rise and promotion of neoliberalism in the country has shaped the economy and politics of health and welfare since the late 1970s [28].

Although the findings from this study indicated that the participants accept the expectation of being responsible for their health and value being their own health managers, they also revealed that this expectation was often not in line with their skills/situations. The result was the emergence of information gaps limiting their options to be responsible and make informed health decisions. The "A gap between expectancy and ability/context" category describes three interlinked subcategories: **digitalisation**, **personal contact** and **navigation gaps**. Numerous studies have reported challenges among older adults to participate in or benefit from the growing digitalisation, known as the "digital divide" or "grey digital divide" [29, 30]. Research findings from Iceland also highlight this information gap. Palsdottir [31] has reported an increased frequency of online health information seeking among people 68 years and older from 2002 to 2012. However, the usefulness of that information, including websites by the health care system or health specialists, did not increase. A study on perceived barriers to health information among people 60 years and older also reveals hindrances in the availability of information and the ability to seek and find it [32]. This divide is considered to marginalise older adults, among other groups, who are most likely to become excluded from the benefits of digital technologies [30]. One solution to the digital transformation that healthcare is undergoing [29], and in line with the expectation of individual responsibility, would be to modify HL by interventions aimed at strengthening the digital skills or competencies of individuals through education. However, Bittlingmayer and Sahrai [33] drew attention to what might happen if increased education is challenging to manage – for example, in the case of disability. Although older adults are a heterogeneous group, this perspective could be reflected, for instance, in the normal ageing process. Lifelong learning [5] should always be an option; however, how health services meet the complex needs of people as their own health managers needs to be addressed. Another angle regarding these experienced information gaps is that limited HL has generally been related to lower levels of education [4, 6, 16]. In this study, however, the community-dwelling participants' education level is relatively high, with most having a secondary or a university degree. Perhaps this echoes the dynamic and complex interaction between various personal and environmental contextual factors acting and interacting as barriers or facilitators of HL.

Because of the gaps experienced in health-related information, the participants need to adapt and find other ways to manage. They do this by, for example,

relying on people close to them like spouses, children, grandchildren and friends, as described in the category “Finding one’s own ways”. Concerning this adaptation, the resilience and resourcefulness of the participants seem to play an important role; it also identifies the importance of social connections or networks. Making reasoned health-related decisions and navigating the healthcare system can, therefore, build on if you have someone in your life willing and able to help. Findings from this research indicated that, in some cases, this support is provided by healthcare staff, even when not on the job. The importance of relatives as an adapted or alternative strategy while dealing with health information was one of four main themes in a study among socioeconomically disadvantaged adults in Switzerland [13]. This supports the importance of social connection and support for those experiencing health-related information gaps. Although matters of caregiving and the share of informal/unpaid carers, often female family members or friends [34], are beyond the scope of this research and will not be addressed further, the effects of individualism and healthcare delivery systems’ expectations of responsibility cannot be underestimated. The local senior NGOs in Iceland also seem to play an important role in providing relevant health-related information, for example about rights and available services. However, to participate in gatherings these organisations provide or to receive most of the information, people must become members and pay an annual fee [35].

In the category “Bridging the gap”, the participants ask for two things to make the passing of the experienced information gaps easier, presented in the subcategories “Shared responsibility” and “Manageable options”. Although the findings from this study indicated that the participants accept the expectation of responsibility for their own health, they also revealed a contradiction. Namely, without knowing what information and services exist and are current, this expectation can sometimes be hard to live up to, or even be impossible. Shared responsibility in providing older adults with more fundamental health-related information seems a vital preliminary step for them to access, understand, appraise and use information. Access to healthcare is generally considered a multifaceted concept consisting of the interaction between the accessibility of services and the abilities of people [36]. One of the five identified dimensions of accessibility is the approachability of services. This dimension includes making services known and reachable to individuals, along with the necessary individual skills to identify the need for these services [36]. Yet again, the complexity of HL is brought to light, and the question is raised where this line between individual versus service responsibility is drawn and, more importantly,

who decides. Organisational health literacy (OHL) is an evolving concept [11], especially in the wake of COVID-19, which has transformed the healthcare service [37]. It is described as an effort to transform health-related services to make it easier for people to navigate, understand and use information and services to look after their own health and address the implementation of policies, practices and systems. This concept underpins the idea that HL does not merely depend on the abilities of individuals [11, 38]. Neoliberal policies, with their emphasis on economic value, have often been criticised for negatively impacting access to healthcare by not addressing the structural disadvantages experienced by certain population groups [39]. Furthermore, these policies are considered to contribute to the negative viewing of individuals who are not in the workforce, perceiving them as potentially financially burdensome [39].

Also, older adults may experience decreased functioning over time due to the natural ageing process. This decline can affect their ability and capacity to access, understand, appraise and use health-related information. Focusing on individual responsibility can lead to compromised access to and use of information and services. Therefore, the effect of these policies on fuelling ageism in viewing older adults as a burden must be considered. Ageism has been estimated to cost societies vast amounts [40], and in the United Nations action plan Decade of Healthy Ageing 2021–2030 [5], one of the identified areas for action is connected to changing negative views and actions towards age and ageing.

The findings from this study indicated that the participants not only require shared responsibility in the form of being provided with fundamental health-related information in the category of “Bridging the gap”. The subcategory “Manageable options” reflects the request for information that is approachable, acceptable, appropriate, and available. For example, this study indicates that older adults have a generally positive view of digital development as a part of the future. This finding is also reflected in a study on technology use for health information based on a randomized sample of older Icelanders [41]. However, it seems to be an issue of design, delivery, instructions and support, bringing us to service user participation and inclusion. One of the identified areas for action in the United Nations action plan, Decade of Healthy Ageing 2021–2030 [5], aims at enabling older people to continue to do the things that they value and support the inclusion of their voices not only as service beneficiaries but also as agents of change. The focus is on the abilities of older people and person-centred integrated care and primary health services. Brach et al. [42] introduced the 10 attributes of a health-literate healthcare organisation (HLHCO). The attributes are based on

the OHL concept [11] to deliver person-centred health-care and tackle system-level factors enabling people to access, understand, appraise and use health-related information. One of the 10 attributes emphasises the importance of including the voices of consumers in the design process, implementation and evaluation of health information and services [42]. This specific attribute, engagement and support of service users, has been recognized as one of the most prevalent topics of OHL [38].

Furthermore, in a framework for strengthening the health system's capacity regarding HL, one of the eight suggested action areas focuses on people-centred services based on user engagement and enabling environments [43]. In this study, the participants indicated that they value being their own health managers and take full responsibility for accessing, understanding, appraising and using health-related information, as expected, as part of social norms. However, the lack of options to fulfil this expectation implies that healthcare delivery systems do not always meet the needs of older adults to act on it.

Strengths and limitations

This qualitative exploratory study aimed to gather information about the experiences and needs of older community-dwelling adults concerning accessing, understanding, appraising and using health-related information. One of the strengths of this study is that it gives older adults living at home a platform to be heard. By selecting potential participants purposefully with different backgrounds regarding the place of living, age, gender, education, means of transport and distance from services, variations in experiences were sought. The generalisability of the results was affected by participants being restricted to living in Northern Iceland and including individuals with similar cultural backgrounds. It should, however, be kept in mind that close similarities may exist between Iceland and other northern geographical areas of the world where the culture is labelled Western.

The possible effects of having a spouse present during three of the 20 interviews must be mentioned. Their presence was considered culturally relevant in rural areas in the sense of greeting visitors at home. The spouses also acted as a support and facilitated communication, such as for one participant with early-stage Alzheimer's disease. Memory loss is most often a reason for exclusion from research. However, gender roles and the power balance between couples must be considered, which might have affected the conversations. One interview took place via Zoom. While this may not align with our main findings, older adults' technological skills vary. In times of often hard confinement and isolation of older people during the COVID-19 pandemic, by preparing the

interview setting well, the wishes of this participant to meet on Zoom could be met.

Clear categories emerged based on evident patterns, consisting of direct content, minimal interpretation and remaining close to the original text. In content analysis, the researcher must know the context. Having four interdisciplinary researchers with stated expertise partaking in the data analysis process contributed to the credibility of this research. Although two researchers conducted the primary analysis, regular meetings with all authors at every step of the process were used for reflection on possible preconceptions and consistency between empirical data and the emerging categories and their content. Including a senior citizen with lived experience on the research team further enhanced the credibility of this research. However, the involvement of an older adult in the earlier stages of the research is an aspect for consideration in future studies.

Working on data in Icelandic and English can be both a strength and a limitation. A strength regarding reasonability and accuracy as a thorough evaluation of the meaning and use of words during the translation process took place. A limitation in the sense of possibly misrepresenting the participants' expression in the translation process from Icelandic to English, although three of four researchers are fluent in both languages, should minimise that risk.

Conclusions

The participants in this study experienced expectations of being responsible for accessing, understanding, appraising and using health-related information as part of acting as their own health managers. Although valuing and accepting these expectations, limitations regarding living up to them were revealed because such expectations were often not in line with their skills/situations, despite having a relatively high education level. Information gaps, therefore, arise due to digitalisation, limited personal contact and general navigation complexity within and between health-related services. Therefore, approachable fundamental health-related information, current and quality checked, and inclusive service opportunities are needed to bridge the resulting gaps. It is necessary to critically address the possible influences of politics regarding the views on individual responsibility at a systematic level in matters of health and HL. Such action should analyse if and how those principles shape attitudes, social norms and health services and confront structural disadvantages experienced by population groups. Access to information and services must be viewed beyond availability and include the approachability, acceptability and appropriateness of service users with various abilities and contexts. The findings from this study reflect participants'

experiences of bearing most of the responsibility as their own health managers, while simultaneously having limited choices in acting on it. Policymakers are therefore encouraged to develop services that enable older adults to make reasoned decisions about health and navigate healthcare services in an effective way.

Abbreviations

COREQ	Consolidated Criteria for Reporting Qualitative Research
COVID-19	Coronavirus disease 2019
HL	Health literacy
HLHCO	Health literate health care organisation
HLS-EU-Q	European Health Literacy Survey Questionnaire
NGOs	Non-governmental organisations
OHL	Organisational health literacy

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Authors' contributions

SSG collected, analysed and interpreted the data, drafted the manuscript and was the grant holder. LM contributed to analysing and interpreting the data and drafting and revising the manuscript. SAA and AKS contributed to the data interpretation and revising the manuscript. AKS was also a grant holder. All authors read and approved the final manuscript.

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Availability of data and materials

The datasets used and/or analysed during the current study are available from the corresponding author upon reasonable request.

Declarations

Ethics approval and consent to participate

According to the Icelandic National Bioethics Committee, no further approval from the previous study (VSNb2016060007/03.01) was needed for this continued research (VSN-21-009). Information about the names and social numbers of participants and research numbers from the previous study were kept separate and accessible only to the researchers through special permission from the file holder, University of Akureyri Research Centre. Written informed consent was obtained from all participants. Participants chose pseudonyms at the beginning of each interview, which were used to ensure confidentiality and privacy, and recorded interviews were deleted after transcriptions. This study is not a registered clinical trial.

Consent for publication

Consent for publication was not applicable.

Competing interests

The authors declare no competing interests.

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