Developing Health Information Literacy in disadvantaged and dependent circumstances: the everyday role of Family Nurses

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Abstract. This paper examines the challenges of developing health information literacy (HIL) amongst disadvantaged and dependent populations; and from the perspective of non-information professionals occupying everyday support roles. Our participants were a team of UK Family Nurses providing outreach support to vulnerable young mothers from areas of multiple deprivations. Our data collection methods were observation, interviews, and focus group. Our participants all believe that they have an important role in developing HIL in clients, but are unfamiliar with fundamental overarching infomation literacy (IL) concepts and models. Consequently, their confidence in their own ability to develop HIL skills in clients is limited. We discuss that to extend primary healthcare practices beyond HIL support to HIL education requires not only IL training, but also an appropriate pedagogical approach adapatable to semi-structured problematic situations. We raise important questions regarding approaches to developing HIL in disadvantaged populations.

Keywords: Health information literacy, information literacy, information behaviour, information intermediary.

1   Introduction

This paper explores the role of primary healthcare professionals in providing health information literacy (HIL) education to disadvantaged (socioeconomic) and at-risk (health and wellbeing) populations in the everyday context. HIL is understood as information literacy (IL) in the health context. Recent studies by Buchanan et al [1-2] have evidenced low IL as a significant issue in disadvantaged at-risk populations, and in relation, identified an important information intermediary role in primary healthcare professionals [2]. We sought to explore how far this role extends beyond support to education, and in so doing, explore IL education in the problematic and understudied everyday context.

2   Background

Our understanding of information literacy (IL) outwith education and the workplace is limited. Martzoukou and Sayyad, in a recent review of empirical research examining IL in the context of everyday life, report that, "Despite the clear value of information literacy within the everyday life context, most empirical research has been conducted within educational and workplace settings" [3, p.2]. They report that:

> ...the implications of lacking IL skills within the everyday life environment have not been sufficiently researched...   It is further unclear how people can be supported and empowered to develop effective information literacy practices within the different realms of everyday life [3, p.29].

Similar issues regarding lack of contextual understanding are raised within health fields. For example, McCormack et al [4] highlight a need for a broader social ecological perspective of health literacy that takes into account multiple and complex levels of influence and interaction. The authors conclude that, "Despite these calls for a broader perspective, there have been no systematic attempts to expand conceptualization of health literacy and increase patient engagement" [4, p.9].

Two recent empirical studies of human information behaviour by Buchanan et al [1-2] have contributed to our understanding of context, and provided direction for this current work.

Buchanan and Tuckerman [1], in the first study of adolescent information behaviours in disadvantaged and disengaged circumstances, worked with UK youth aged 16-19 not in education, employment or training (NEET), and their support workers. NEET youth can be considered an an at-risk group. Delinquency rates are higher than peers, as are rates of substance abuse and mental health issues [5-6]. The authors report low levels of IL amongst NEET youth; with NEET youth demonstrating a wide range of unmet information needs, passive non-motivated information behaviours often abandoned, and a dependence upon support workers when seeking information. Such issues are compounded by an impoverished and insular existence, and disengagement with state services including libraries, schools and colleges. The authors report that due to such issues, support workers would not leave NEET youth to find information independently, but would provide or guide them to information. An important support role is identified, but with, "no evidence of proactive transitions to independent information seeking from either party, nor of basic literacy issues being explicitly addressed" [1, p.543]. Remedial IL education is recommend as an immediate priority.

Buchanan et al [2] further explored the everyday support role of non-information professionals via work with UK healthcare professionals providing support to young (<21) vulnerable mothers from areas of multiple deprivations. Young mothers are also an at-risk group. They are more likely to be single parents, to have experienced family conflict/trauma, not to be in employment or education, and at risk of mental health issues [7]. Buchanan et al report low levels of IL amongst young mothers, and similar to NEET youth [1], report this issue compounded by general disengagement with state services and structured learning programmes. Young mothers are reported to have multiple, interrelated, and at times competing information needs, not always apparent or revealed, and often within sensitive situations. Many information needs are reported as unmet without support worker intervention. The authors evidence and define an important information intermediary role amongst support workers with three key contributions to information behaviours in disadvantaged circumstances [2, n.p.]:

1.   In situations of multiple needs, information intermediaries facilitate information needs recognition, and considered purposeful action, that takes account of the problematic context.

2. In situations of insular existence, information intermediaries are a key source of information in themselves, and a key integrative connection to other external sources not otherwise accessed.
3. In situations of poor comprehension, information intermediaries tailor and personalise information for relevance, and communicate via incremental and recursive cycles that take into account individual learning needs.

However, whilst identifying and defining an important information intermediary role, Buchanan et al [2] also note that evidence of dependent relationships also raises important questions regarding transitions to independence in disadvantaged and disengaged circumstances. This study sought to explore such questions further, and in particular, the role of support workers.

3   Methodology

A purposive approach to sampling defined participant inclusion criteria as being a professional directly engaged in support to a disadvantaged population. Our participants were a team of UK National Health Service (NHS) Family Nurse Partnership (FNP) nurses providing outreach (home) support to vulnerable young first-time mothers from areas of multiple deprivations. Nurse visits are from pregnancy to child age two years. Visits are weekly initially, then fortnightly scaling down to monthly towards end of programme. The study zone (team area) was confirmed via the Scottish Index of Multiple Deprivation (SIMD) as within the 5% most deprived decile in Scotland [8].

Young mothers from areas of multiple deprivations, as previously noted [7], are a disadvantaged and at-risk group. Infant mortality rates are higher than for older mothers [9], and babies at greater risk of poor nutrition and care [10]. Stress and anxiety are heightened, as are rates of depression [11]. Low literacy is also reported [12]. Notwithstanding such issues, motherhood can be a positive experience for young people; however young mothers can also be subject to significant societal stigmatisation that encourages marginalisation and disengagement [13].

Our theoretical framework was provided via concepts and models of information literacy (IL). IL was defined as per the American Library Association definition [14], "Information literacy is a set of abilities requiring individuals to recognize when information is needed and have the ability to locate, evaluate, and use effectively the needed information."; and placed in the health context via Scottish Government NHS definition [15, p.3], "Health Literacy is about people having enough knowledge, understanding, skills and confidence to use health information, to be active partners in their care, and to navigate health and social care systems". The Big6 was used as a reference model during discussions to illustrate processes and relate to nurse practices.

Our data collection methods were observation, semi-structured interviews and focus group, conducted over six months, and designed to explore nurse information interactions with mothers and approaches to IL education. Nurses were provided with a tablet PC and mobile Internet access. Tablets were bookmarked to YoYo [16], a digital resource tailored to the information needs of young mothers and providing access to state and third sector information sources. Nurses were free to use tablets as deemed appropriate and were under no obligation to use YoYo during their interactions with mothers. Previous to provision of equipment, nurses had no means of digital access during home visits beyond their own personal mobile phones.

Observation was conducted prior to interviews to provide a degree of immersion and appreciation of the research environment. The researcher attended team meetings, and accompanied nurses on home visits. Two rounds of individual semi-structured interviews followed observation. The

first round explored the nurse role in helping mothers locate, access and use information. The second round explored nurse understanding of IL concepts, and approaches to IL education. A focus group followed interviews and began with semi-structured discussion, followed by open discussion. Participants were provided with summarised interview findings and invited to comment on validity. Participants were then asked to discuss their IL role, approaches to IL education, and factors influencing IL interactions.

Data analysis incorporated deductive and inductive elements, with data disaggregated into meaningful categories via identification of patterns and regularities through iterative pattern coding and thematic analysis. Initial start-list codes were based on concepts of IL. Further codes were emergent, in particular those relating to IL education, and influencing factors.

Ethical approval was obtained via Institutional Ethics Committee, with the study run in strict accordance with the University Code of Practice on Investigations of Human Beings.

4 Findings

Our six family nurse participants, who formed the area team, were aged 36-51 (avg. 43). All were University qualified, and collectively posssessed 105 years professional experience in healthcare (avg. 17.5), with the majority of time spent in family community support roles. The combined caseload of participants was 89 young mothers, with the majority yet to give birth.

When asked how frequently participants used digital sources of information for their own professional and personal purposes (to ascertain general levels of digital engagement of participants), the median responce for both was 5, equating to 'very often'.

4.1 Observation

Observation was primarily intended to sensitise the researcher to the research environment; however some observations are notable. Nurses were observed taking time to discuss individual everyday needs of mothers (many poverty related), and flexibly accommodating such needs alongside delivery of FNP programme specified learning outcomes (e.g. mother health, homebuilding, personal development, pregnancy and child care, relationships). Nurses were also observed bringing various resources to deliver and support individual learning needs, ranging from the provided tablet PCs to leaflets and visual and demonstrative props such as foetal dolls. Information interactions could thus be considered semi-structured, nurses being responsive to everyday needs alongside prescribed and planned programme aspects.

4.2 Interviews

When asked how frequently participants used and/or referred to digital sources during their interactions with mothers, the median response was 2, equating to 'not very often'. One participant had no digital interactions whatsoever. Whilst digital use was low, all participants felt digital had an important role and valued YoYo for providing direct access to trusted and tailored information. Examples discussed included providing access to visual resources to aid learning, such as videos of children's games and nursery ryhmes, and techniques for effective breastfeeding; and in sensitive situations such as instances of domestic abuse, being able to refer clients to digital sources that avoided leaving print material behind that perpetrators might see (note. YoYo includes a domestic abuse link to Scottish Women's Aid). YoYo was also valued as an alternative to Google searches. For example, one participant commented:

I'm probably not using it [YoYo] to its full potential at the moment but... it could be really

helpful... if I got used to using it in visits with my clients, hopefully... that would be their first port of call... when they want information they'd go to that cos of as you know, learned behaviour is what you do. I think the majority... it was Google, Google, Google.

Low digital interactions were largely attributed to access issues. For example, one participant commented, "Technical issues just due to where you are and maybe not having Internet access". Participants also discussed how many mothers had limited or no digital access, and whilst public libraries offered access, they were not used. For example, one participant commented, "...the majority they don't go to the library... if they've got phones they've got limited data or they have poor network connections". And another, "I've got a couple of clients who don't even have a phone never mind a Kindle or laptop or anything..."

Another challenge to digital interactions was time. For example, one participant commented, "Each of our programme visits usually would last about an hour and we've got a certain amount of information that we would try and share... and we know that if you deliver the programme... you are more likely to get the outcomes for the young women and their children". And another, "We do have a lot of paper... that's the programme that we're delivering that takes a lot of time in those visits as well as addressing whatever other issues will be there for clients. Getting time to sit with the pad [tablet] and spend time, that can be quite challenging". Further challenges related to interpersonal communciation preferences. For example, one participant commented, "I just feel that the mums themselves are thinking, 'well I can look that up later'. They are more kind of wanting the time for a kind of one to one verbal kind of chat." And another, "To try and fiddle about with your phone, to try and skip along is not particularly easy... when you are trying to engage with them".

When asked if prior to interviews, participants had been familiar with the term information literacy (IL), five responded no, and one yes. When asked if they had completed any IL training or qualification, five responded no, and one yes. For the participant who responded yes, this was in relation to a postgraduate healthcare degree. When asked if IL had been explicitly covered they replied, "I suppose probably not specifically". When participants where asked if they were familiar with IL models or frameworks, five responded no, and one yes; however, the respondent who replied yes could not recall a specific model or framework.

When asked how confident participants felt in their ability to develop IL in clients, the median response was 3 equating to 'somewhat'. Several participants explained that whilst not familiar with IL concepts, they had a degree of confidence in their ability to develop IL skills in clients due to feeling that they understood IL concepts as presented to them during discussions (see methodology). For example, one participant commented:

> I think because that's the first that I have seen that model [IL reference model], so I like to get more information and look at things and make sure that I am doing it right, so it's probably just because that's the first I am seeing that, that when you talk about information literacy I think yeah OK – when you explain it I know what you're talking about so I should be able to implement that in practice OK.

All participants felt that they had a IL education role in relation to the overaching goals of the FNP programme to develop client self-efficacy (i.e. client belief in their own abilities). For example, one participant commented, "Well we're not going to be with them forever... we're trying to give these girls the skills to find out information in life". And another, "I do feel I have a [IL] role because... part of the FNP programme is about self-efficacy and about people being able to do things independently and get the best possiblle information for the best possible outcome for them and their baby".

When asked how they developed IL skills in clients, the majority discussed this in the context of meeting information needs, and conducting searches for mothers. For example, one participant

commented, "I think it's [IL] something we do on a day to day basis... well for a lot of our clients it's really helping them understand their needs before you can even move forward to how we go about meeting those needs". And another, "I suppose... it probably depends what the topic was, if I was able to find that information, but it's then about navigating through that particular system then as well in order to find the right answer for them as well too".

All participants discussed how for interactions to be effective, it was important that information was meaningful. For example, one commented, "...it's got to be something that they are interested in, it's got to be something that they want to hear". Several discussed using the elicit-provide-elicit motivational technique to understand and meet needs. For example, one commented, "...it's finding out what they know, what they need to know, because... everybody has different information, everyone has different knowledge". Participants also discussed the need for sensitivity to circumstances. For example, one commented, "...you are trying to maintain a therapeutic relationship... a lot of these young women are quite volatile because of their situation and in order to change, sometimes you have to push a wee bit".

Participants discussed several challenges to effective information interactions, categorised as: determining individual information needs, changing online behaviours, transitioning from dependent relationships, and participant digital skills.

All participants discussed dealing with multiple and varied information needs on an individual basis. For example, one commented, "all clients are different", and another, "everybody's individual". Participants also discussed how individual needs could be difficult to elicit. For example, one commented, "Some of the clients can be really quiet you know... and they might not feedback much", and another, "I have one client who is very, very quiet... I think she potentially finds it difficult to communicate verbally". Low self-esteem and confidence were considered significant contributory factors. For example, one commented, "...she has lots of issues with low esteem and low confidence coming from her own adverse childhood experiences", and another, "Sometimes they don't want to know. Sometimes they don't have the confidence". Such issues impeded effective interactions. For example, one participant commented, "...they feel really judged... they don't want to ask questions so that's not helpful, they don't fully talk about the issues which they have because they think somebody is going to judge them". Individual learning needs were also highlighted. For example, one participant commented, "...some don't have the literacy skills, they are not able to read and write".

All participants discussed difficulties in directing mothers to reliable information sources. For example, one discussed how when she had asked mothers if YoYo had been used between visits, had recieved a common reply of, "No, I just used Google". The participant commented, "I think it's a cultural thing. It's just what they're used to doing and I think I probably need to be better at kind of keeping going back to the resource and maybe it will start to kind of mirror them using it I suppose". Another participant also highlighted the importance of regular reinforcement, commenting, "I think its just about all the time reinforcing what the helpful sources are". Another participant, also discussing a reluctance amongst her clients to use trusted sources such as state websites, commented:

> They would start to do it [use state provided information sources] and then it would get a bit complicated and... then they would give up I suppose and maybe even get sort of waylaid... find it difficult to know where it is pointing them to... maybe the language isn't always particulalry useful for them or they don't maybe understand it.

Several participants felt that they themselves would benefit from digital skills training. For example, one commented:

> I would love someone to help me to go in and work certain things out... on the phone or computer... to help me be better at doing that kind of thing so that I could then pass that on or

at least be more knowledgable than I am at the moment about... carrying out searches and things cos you know I'm probably not brilliant at doing that...

Another commented:

I think for... nurses or practitioners in general it would be great just to get more information ourselves and maybe more training... perhaps have something that would... be specific to the FNP programme that you could always get information from... that the client could also use... and we could all be singing from the same song sheet really and you would know it was correct up to date info... that would be beneficial.

Transitioning mothers from dependent relationships could also be a challenge. For example, one participant commented:

...a lot of them expect maybe their parents..., or... older siblings, to do a lot for them... I think they are maybe used to other people carrying out these kind of tasks for them, so sometimes they then maybe expect myself to then go and kind of do it for them too.

4.3   Focus group

Participants agreed with summarised interview findings including confirmation that they all felt that they had an IL education role.   In the discussion that ensued, a number of influencing factors were identified: alignment with primary care priorities and constraints; relevance and application of IL models; role modelling as an instructional tool; and participant training needs.

Participants discussed the challenges of attempting to develop IL skills alongside primary care responsibilities and FNP learning outcomes.   For example, one commented:

We usually have at each visit a lot of written material... we do a lot of agenda matching as well but we still have a lot of information at each visit... we may also have a developmental review to do... we're also maybe going into visits where the situation is chaotic or our clients have their own agendas that we have to address first... sometimes even trying to get any learning into a visit for some of our clients is a challenging thing to do... if I was to say what probably the most difficult thing is, it would be the time factor...

Another commented, "I think at times it [IL] can be our role but at other times then we can't get too embroiled in things like that cos we need to still look at what we're in to look at".   And another, "I suppose we've got to prioritise each visit and what that's about and obviously the child is at the centre of that as well, but aye [have an IL role]".

Participants discussed whether or not an IL reference model would be useful during interactions, and whilst initially dismissed, was upon further discussion, considered relevant.   For example one commented, "Naw [no]. I don't think so."   However another commented, "That [IL reference model] might be quite helpful as a facilitator in terms of discussing it with them... how do they start to go about searching for information that's relevant... cos some of them do need it broken down".   The participant who had dismissed the model then replied, "Aye [yes], actually I done all those stages" and later commented, "I think it would be good reflection if they've done something then say 'Look, you've done this'[refers to IL reference model]".   However several participants also voiced concerns regarding how such a model might be understood by mothers. For example one commented, "I don't know how well our clients would be able to understand a model like that", to which another replied, "Just a few of them I suppose", and the first to reply, "Probably the ones that would understand it would be the ones that wouldn't have the same amount of difficulties in the first place".

Participants felt that the best way to impart good IL practices would be to do so through role modelling.   For example, one commented, "Role modelling..., doing it yourself, doing the steps

and showing them how to do it themselves – so if you did it enough times then perhaps they would go through the stages". Another commented that an IL pocket guide would help:

> If you had it [IL model] laminated in your diary and you maybe said 'right we've got a problem, why don't we try and break it down like this', and then... use role modelling... and using it as a framework [to] tick boxes – right I've done that stage, I've done that stage.

Participants also discussed gradual transitions to self-efficacy. For example one participant, discussing mothers with no understanding of state welfare entitlements and processes, commented:

> There's a bit of a need for fixing initially... we sometimes get involved in supporting them... you are doing things initially and gradually over time you try to kind of withdraw. I suppose you can think about sharing information in a similar way, initially you are pointing them to where things are and then you are gradually withdrawing - so they have a site [information source] that they feel confident going into.

In relation, participants discussed how it could be difficult to change bad practices amongst mothers. For example, one commented:

> A lot of our clients look for a kind of quick fix. That reflects the society we're in... we've got the time to be talking about [information topics] over a long period of time so... that they've got a better understanding... but that can be challenging if you are trying to work through a process... and they go on a blog or social media and somebody has given them, 'this is how you cure this, this is how you do this', which probably isn't the case...

Participants also discussed their own training needs to be able to develop IL skills in clients. For example, one commented, "I think I would appreciate any [IL] training really – if I was going to be able to help my clients then obviously it would be good for me to feel very confident in what I was saying...". And another, "It [IL] is a critical part of our job when you think about it... although we do a bit around MI [motivational interviewing] in the training, there's nothing really about IL". And another, "I think it's [IL] probably something we would do, it's just we didn't know that it was called that". And another, "We are using it [IL] a lot, but you know I think I didn't really understand there even was a [IL] framework".

5   Discussion

Our participants play an important role in supporting and meeting the information needs of disadvantaged young mothers. Alongside delivery of the FNP programme, interactions are responsive to the everyday information needs of mothers. An important information intermediary role appears evident, supporting previous findings [2]. Digital resources are recognised as important, but are not used often during interactions, primarily due to issues of access and time. Our study draws further attention to enduring issues of digital access amongst disadvantaged groups, and, notably, evidences such issues extending to frontline professionals providing outreach support, professionals who prior to this study, had no means of digital access in the field apart from via their own personal phones. Several of our participants also felt that they would benefit from digital skills training.

Our participants all believe that they have an important role in developing information literacy (IL) in young mothers, but the majority are unfamiliar with IL concepts, have not received any IL training, and are not familiar with any IL frameworks. Consequently, whilst feeling that they intuitively understood IL concepts as presented during discussions, they are only 'somewhat' confident in their abilities to develop IL skills in their clients. Further, there is limited evidence

of transitions to independent information seeking or underpinning pedagogical practices to achieve such goals, supporting previous findings in similar disadvantaged and dependent circumstances [1-2]. Notably, our findings evidence an IL skills gap amongst primary care health professionals, and raise important questions regarding approaches to developing IL in disadvantaged and dependent populations. It could be argued that our nurse participants do not have a responsibility for the IL education of their clients, but if not them, then who? Librarians appear an obvious alternative, but this study supports previous findings that young mothers do not use libraries [2]. In contrast, our nurse participants appear used, and importantly, trusted by a vulnerable, stigmatised, and disengaged group [2,12]; and by the nature of their intermediary role, appear ideally placed to deliver IL education via meaningful tasks focused on real information needs, a factor considered integral to effective IL programmes [17]. Further, the Scottish Government, in their Health Literacy Action Plan 2017-2025, have articulated an important IL role amongst primary healthcare staff, and have a stated aim to, "embed ways to improve health literacy in policy and practice" [18,p21] that includes to, "develop practitioners and design services that are responsive to people's health literacy needs" [18,p39]. Thus an IL role is evident in practice, and warranted in policy. The challenge appears to be how to extend health professional practices beyond IL support, to IL education. We reserve this important question for future research.

6   Limitations and further research

Whilst drawing on the cumulative experience of a team of health professionals, we nonetheless report within the constraints of a single case study. However, given the potential significance of our findings, we would call for further research to explore our findings with further groups.

Further research is also required into appropriate pedagogical approaches to IL education that are adaptable to semi-structured everyday situations, and implementable by non-information professionals in the problematic context. Recognition of information need appears particularly problematic, and whilst being a fundamental first step in IL models, it is arguably not addressed in sufficient depth within existing models for semi-structured everyday situations such as this.

7   Conclusion

Our family nurse participants play an important role in recognising, understanding, and progressing the information needs of vulnerable young mothers. An important information intermediary role is evident in participants, but with limited evidence of transitions to independent information seeking in clients, or of underpinning pedagogical practices to achieve such goals. Our participants all believe that they have an important role in developing IL in clients, but are majority unfamiliar with IL concepts, have not received IL training, and are not familiar with any IL frameworks. Consequently, their confidence in their own ability to develop IL skills in clients is limited. Further challenges include how to incorporate IL education into primary care responsibilities, and issues of digital access.

Our findings suggest that to extend the practices of healthcare professionals beyond IL support to IL education requires not only staff training, but also an appropriate pedagogical approach adaptable to semi-structured and problematic everyday situations. In relation, information need recognition appears particularly problematic.

Beyond empirical and theoretical contributions, our findings also have practical implications. We evidence an IL skills gap amongst primary healthcare professionals, and raise important questions regarding approaches to self-efficacy in disadvantaged populations.

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